English (US)

00:00:04.160 — 00:00:13.040 · 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 Michael J. Fox.

00:00:15.040 — 00:00:37.280 · Veronique Enos Kaefer

Navigating Parkinson's disease can be challenging, but we're 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 Michael J.

fox.org.

00:00:41.800 — 00:01:27.990 · Lydia Anderson

Welcome to another episode of the Michael J. Fox Foundation Parkinson's podcast. I'm Lydia Anderson. On November 15th, 2025, the Michael J. Fox Foundation hosted a roundtable in New York City to hear from leading Parkinson's experts in a series of panels. They covered advances in lifestyle medicine to treat Parkinson's.

A vision for a world free from the disease and how. Advocacy for Parkinson's policy will shape the future of Parkinson's research. We wanted to share those conversations with you. You'll hear from Veronique Ines Schaefer, lead philanthropy director at the Michael J. Fox Foundation, as she moderates a series of three conversations with researchers, clinicians and people living with the disease.

What follows is that audio, beginning with a panel on lifestyle medicine featuring Doctor Bastian Blum, Doctor Rachel Dolan and Jon Nathanson.

00:01:28.550 — 00:02:04.060 · Veronique Enos Kaefer

Hello, everybody. Welcome. This first conversation we're having is about the science of how lifestyle can improve our experience with PD, along with medications. Let's dig in. Let's meet our panel doctor, Bastian Blum. You are a neurologist. You work with Radboud University Nijmegen and the Netherlands.

You're the director of the Radboud Center of Expertise in Parkinson's and Movement Disorders. Fun fact you are ranked within the top 1% of most quoted doctors in the world since 2010.

00:02:05.660 — 00:02:21.700 · Veronique Enos Kaefer

Um, you were on the Dutch national volleyball team. You practice lifestyle in your own life. Why? You've done extensive research. Why did you decide, as part of your research, to focus on the science behind lifestyle.

00:02:21.740 — 00:03:33.860 · Dr. Bastiaan Bloem

So when I started my career as a 21 year old, I was about this big. It was with Bill Langstone. I had no idea who he was, and we studied balance, posture and stability in people with Parkinson's. And one of the key findings of my PhD work is that the medication doesn't really help much for balance. It may even make things worse.

And at the same time, as a former professional athlete, I was a semiprofessional volleyball player. I was convinced that physiotherapy helped. We needed to prove it. So we put science behind my belief. And now physiotherapy is an evidence based class one Strategy to fight gait and balance problems in people with Parkinson's.

And that included exercise. So as a former athlete, I was convinced about the benefits of exercise, but also as a clinician, when I face people in my clinic, the ones that are doing best are the ones that faithfully exercise and adhere to a healthy lifestyle. So I'm not against medication. People often think, oh, is the goal of lifestyle?

To reduce medication, no. You need to be in a good on phase to get a good workout, so you need both. They interact. But people in my clinic who say, look, bloom, help me, I want to help. But I also say, I'm tossing the ball back to you and go to work.

00:03:34.100 — 00:04:21.329 · Veronique Enos Kaefer

All right, doctor Rachel Dolan, many of you know Rachel from Akhmed third Thursday webinars and all that she offers for our community. You are our very own in-house movement disorder specialist and lifestyle medicine physician, our principal medical advisor. You practice neurology, you are integrated with the patient and research Communities.

You also practice the benefits of lifestyle medicine in your own life. You run three marathons. You just ran the marathon in Germany. Berlin. You practice healthy nutrition. And also you're, um, really interested to know a lot about, like, meditation, uh, mindfulness practices as well. So as a neurologist, as a medical advisor, you were already doing so much.

Why did you get additional certification in lifestyle medicine? What does it mean to you?

00:04:21.329 — 00:06:12.630 · Dr. Rachel Dolhun

It's similar to what boss said, which is I heard from the community. So so I don't have my own practice, but I feel like I have a practice of 1.5 million people who follow us. I get to interact with on an individual basis. And so I hear from people on a regular basis and on panels like this, it didn't matter what we were talking about.

The questions were always, what's the best exercise? What should I be eating? And I felt like we didn't have good enough answers. And when I left practice in 2014, I will say I said to my guilt, I'm guilty of saying to my patients. Medicines are the tools in my toolkit because that's what we learn as doctors.

But I heard from the community over and over and over. We want more. We need more. We need places where we can take action and we can take control, and we can positively influence this journey that we don't have as much control over. And so things like exercise, diet, mindfulness, meditation. We've seen as as you mentioned, we've seen the value that people have reported back to us when they're practicing these in their own lives, and they aren't a replacement, but they help the transformative treatments that we have work even better.

And they also really fill in the gaps where on freezing, on constipation, on other non motor symptoms where we don't yet have good enough therapies, they really help us fill in those gaps. And the last thing I'll say is in addition to the science and proving it, I think one of the things I've become very passionate about is really helping people implement them, because everybody in this room probably knows you should exercise, right?

But it's really about how do we actually do it when life gets in the way, when Parkinson's gets in the way. And so I'm really interested and invested in helping people really bring these tools in practical ways into their own lives.

00:06:12.670 — 00:06:33.190 · Veronique Enos Kaefer

Jon Nathanson, thank you for being here. Jon, you are an architect. You are an artist. I'm sure you and boss will have things to talk about. Your interior designer, product designer.

You have a life that you love. You were diagnosed with Parkinson's in 2017. How have you used lifestyle and medicine to continue living the great big life that you want to have?

00:06:33.230 — 00:08:12.340 · Jon Nathanson

I think the first thing that I have to say is people present exercise as something like, that's bad medicine, that doesn't taste good and it's difficult. My, my message is just move. Just get up and move. I mean, this is so important that all the specifics about what sort of exercise you do and what the focus is, is, um, you just need to start.

And I have found great support systems in what I do. Um, I box with a group, and it's run by two professional boxers and a neurologist, and they push us to the limit. And so rather than presenting exercise as something that's palliative, it's something to get involved with and be inspired by working as hard as you can and feeling the benefits.

We all need help with this. And, um, I've been playing pickleball with a group that's set up for people with Parkinson's and volunteers, and it's an incredible way to to have a good time to get fit and to have a relationship with other people living with Parkinson's. I mean, that's part of the issue is that we are we are somewhat invisible.

Um, and to find groups where people with Parkinson's are pushing themselves beyond what their own expectations are. It's really critical and I've had a lot of help. I've had many people who have supported me, and I've been trying to give back by being a member of the Parkinson's Wellness Foundation and organizations that want to fuse together wellness, movement, lifestyle choices and keep us all going.

So I'm really grateful for that.

00:08:12.900 — 00:08:26.740 · Veronique Enos Kaefer

All right. The science behind exercise. Doctor Bloem, you've done many studies over the last several decades. What are the mighty themes, the mighty lines that rise up for you about the science of whether exercise helps Parkinson's?

00:08:26.780 — 00:11:02.270 · Dr. Bastiaan Bloem

So there's three really interesting components. One is it suppresses symptoms just like a drug. So it helps to alleviate motor symptoms. But also the non motor symptoms it improves sleep. It improves constipation. Slow bowel movements are bad for people with Parkinson's. If there's any folks out here with slow bowel movements.

Get it fixed because your medication won't work as well if you have slow bowel movements, and exercise is one of the ways to fight it. So it works as a drug, which means if you stop, you lose the benefits. The second element, and this is works sponsored by the Michael J. Fox Foundation, is that if you faithfully exercise, the brain makes new connections between the diseased basal ganglia and the healthy cortex, meaning that the brain's healthy brain areas start to take over functions of the damaged brain areas.

Now, what I do in my clinic, I face people with Parkinson's, and I say, if you look at the treadmill and you're not motivated, I tell you, all these new connections in the brain. I mean, it's deeply motivating. It might become the very first disease modifying treatment that can slow down Parkinson's. We've seen one disappointment after the other with drugs that try to slow down Parkinson's.

One of the reasons is that the pathophysiology, what is happening in the brain of people with Parkinson's is complex. It's mitochondrial problems, it's inflammation, it's protein accumulation. And the drugs typically take only one of those processes. So if only one process is stopped and the others continue, disease progression might go on.

So either we need a poly pill. You know we treat HIV with three pills. We prevent strokes. With three pills we treat tuberculosis with three pills. Maybe we need to treat and slow down Parkinson's with a poly pill. But that's not likely to going to happen soon. Or we take an intervention that, by virtue of its very nature, is pleiotropic in nature.

That tackles multiple mechanisms. And that's exercise, that's nutrition, and that's stress management. So it could be disease modifying treatment. So we are so convinced that it can slow down Parkinson's. That one I wondered if in a ward in Holland this is the Dutch Nobel Prize for science, 2.5 million.

And we invested it in the slow speed study, which is the world's very first disease modifying intervention in prodromal Parkinson's, trying to stop the disease from happening, or postpone it by delivering a home based exercise intervention. The Michael J. Fox Foundation is now a co-founder of this study by developing the tools to measure progression in prodromal Parkinson's.

Very encouraging and fascinating word.

00:11:02.390 — 00:11:14.070 · Veronique Enos Kaefer

So what I'm hearing is that exercise can literally be disease modifying. We're always looking for therapies that can be curative or slowing things down. And this may be true.

00:11:14.110 — 00:12:43.300 · Dr. Bastiaan Bloem

Yep. What Rachel said was essential because how do you do it. So the problems in clinical practice is a the doctor doesn't think about lifestyle or the doctor says, look John, you gotta exercise, lead it, eat well and manage your stress by. And then people say what? How? Now if we just take take exercise one component is the aerobic component.

Don't titrate it to your heart rate, because we know cardiac innovation is abnormal in people with Parkinson's. That's nothing to worry about. It just means you can't titrate it to your heart rate, titrate it to your breathing rhythm, which means that you need to pant, have shorter conversations, but you can still speak.

That's the right dose every day. And why every day. If you exercise three times a week, which is the norm, there's always tomorrow. No ifs, ands or buts. Every day, 30 minutes. And now comes something really cool. People often say I don't have 30 minutes. The latest work is showing that if you exercise for one minute, take the stairs instead of the elevator.

That's an exercise snack. So instead of olives or chips, you now do exercise snacks and 30 times one minute is as good as one block of 30 minutes. And the second component is simply the volume of exercise taking more strides. And it plateaus at about 7000 steps. So target your exercise to an aerobic workout plus 7000 steps per day.

That makes it practical.

00:12:43.540 — 00:13:24.740 · Veronique Enos Kaefer

Thank you, Doctor Dolhun. I know you have 20 years of experience working with people, talking to people. Is there more you want to add about what's the right kind of exercise? And also I'll tag a second question. And people often ask, they say, I know that there's research happening and that there's progress.

I want to experience that in my life from what you've seen. So there have been 17 new therapies that have come to market in the last ten years. New medical devices, 50% of them are about treating symptoms, 50% of them are about disease modification. People are adopting more lifestyle approaches. Do you think people now are living better with Parkinson's than perhaps 20 years ago?

00:13:24.820 — 00:16:05.110 · Dr. Rachel Dolhun

So interestingly, about exercise, you know, we default to thinking about cardio or aerobic, right? Cycling, running, walking, swimming. And that is key. And that's core. And that's what you were talking about with the torque test and getting that in at least three times a week, hopefully five 30 minutes at a time.

But it's so much more than that. So it's also strength, body weight exercises, adding weight that's especially critical in Parkinson's and especially critical for women who are getting older. So osteoporosis, thinning of the bones is more common in people who have Parkinson's. People who have Parkinson's also are at risk for falling for having fractures.

So we want to strengthen the bones the best way we can. And similar to what you were saying, we're not saying exercise is the cure all. You have to take your vitamin D, maybe calcium, you have to get your sunlight. But exercise is another tool to help support your strong bones. So you've got your cardio, your strength, and then also balance and flexibility.

So stretching, doing your balance exercises. Now that by itself can seem like a full time job, right? How am I supposed to get in this 30 minutes. And then now you want me to lift weights too? And then I'm supposed to also socialize. And so we have to think about where are the ways that one we can combine exercises.

You mentioned boxing. So that gets a lot of things. It gets our balance. It gets our aerobics. It gets our community. Sometimes we even get speech exercises because we're yelling at the bag, hopefully not other people. And so so we brings in all of these components. And so there are ways, whether it's spreading your exercise out through the day or combining with these kinds of programs, that you can get these multiple components of exercise in.

Um, the other thing I'll say is interestingly, on your point about the doctor saying, you know, exercise, eat well, control your stress, and see, in six months, um, ask your doctor, ask your physical therapist, ask your exercise program to prescribe exercise for you. So I heard this great way of this being said one time by another researcher who said, if we prescribed medicine like we sometimes prescribe exercise.

It would be ridiculous, right? If we said, take an aspirin, whatever dose you feel like, whenever you feel like it and you know, and then and then let me know how it works. Right. So, so yes, we want to meet people where they're at. Yes, we want to get movement in. That's just as important as structured exercise.

But we have to be better at supporting people. With what specific exercise should I be doing? How much, how often. And so that's something that you can work on with your team as it is now to get that additional support in.

00:16:05.150 — 00:16:26.830 · Veronique Enos Kaefer

All right. So we've been talking a lot about exercise John. There are actually six pillars to lifestyle exercise nutrition sleep stress management human connectedness and avoidance of risky things substances and behaviors. When you think about those things in your life, which are the things for you personally that have risen up and that feel most helpful?

00:16:26.950 — 00:18:04.900 · Jon Nathanson

I think for me lately, um, is the type of movement that we've been doing in boxing and dancing classes and what's what I guess I never understood before is the shadow boxing is based on a variety of movements where the the professional boxer teaches. This class says move to move, move one two, three left, 123 right.

Giving you what types of punches throw what direction you're going in. And it seems extremely undoable when you first start. And then all of a sudden your brain and your body kind of connect in a way that is, um, transcending. Um, and this is the value of things like dance and boxing that it takes it out of your brain and it puts it in your body and in your spirit in a way that is, um, difficult to describe.

But I find it very useful. Um, it's on top of other things like pickleball, also similar that you can't think and play. You learn how to think, play and movement becomes more joyous. I think the other thing about the recent exercises that I've been doing is that it's it's part of a group, so there's a social component to it.

And also you're doing it with people with Parkinson's that we're, you know, we are in a day to day life. I think we are largely invisible. And if you can find a group that has people who are living with Parkinson's, working and pushing themselves, you benefit by identifying with the person and also keeping up, well, connecting.

And that's really important.

00:18:05.260 — 00:18:15.860 · Veronique Enos Kaefer

Stress management. Doctor Dolan, what can we do? Stress is a part of life for everyone, but it's more in people with PD. What are some approaches you found are helpful?

00:18:15.900 — 00:20:45.590 · Dr. Rachel Dolhun

So stress is a normal part of life, right? It's not reasonable to think that we're able to get rid of stress. So it's that whole concept of controlling what you can control, right. So you can't get rid of all the stress. But we can find tools and ways that we can manage the stress. As you pointed out, people with Parkinson's report having more stress than people without Parkinson's.

I always emphasize that stress is not just a mental condition, it is actually a physical condition. Your body is releasing stress hormones. Those are impacting your bodily health and also your brain health. So it's really critical that we look at stress just like we look at any other thing that we know is not good for us.

I think you and colleagues did a questionnaire study on asking people with Parkinson's, one about their stress, but then also about what tools do you use to manage stress. So the good news is that physical exercise I think rose to the top. So again, another way we can combine things not only with exercise are you getting the benefits of exercise itself.

But if you do group classes you're getting social connection, which is another one of our pillars. And you're also potentially getting stress management. Mindfulness was not as high on there and I think part of that is because people, a lot of people don't understand what mindfulness is or think that it's meditating on a cushion on a mountaintop or in a dark room and getting rid of all of your thoughts.

And really, mindfulness is something we can do anywhere, anytime. It's bringing yourself in the present. So what right now? Am I feeling this microphone digging into my back? I'm a little cold with the air blowing on me, you know? What exactly am I feeling? Seeing, hearing, tasting? Thinking? It's not about getting rid of your thoughts.

It's about knowing what those thoughts are. So bringing ourselves into that present moment. Because right. If we're thinking about the past, maybe there's regret or sadness or things like that. If we're thinking about the future, maybe there's anxiety, uncertainty, worry. So again, it's really just grounding ourselves, bringing ourselves back into the present.

And the beauty of it, as I said, is it's something you can do anywhere, any time. So that may not be for everybody. But the point is it's a great tool. There's exercise, there's journaling, there's praying. There's all kinds of things. So it's really about looking at all those different things, making it a fun experiment, testing and learning and finding a couple of tools that, you know, work for you that you can pull from no matter what the moment is that you need to manage.

00:20:45.830 — 00:20:59.950 · Veronique Enos Kaefer

All right. Human connectedness, John. And then Doctor Bloom, um, what is your support network look like? Everyone's is going to be different, but how does yours help? And then Doctor Bloom, it will be. Is there research that supports human connection?

00:21:00.110 — 00:21:44.310 · Jon Nathanson

I'm lucky to have people who love me in my life and who I love, and that's the the key to my support. I'm also an artist, and one of the things that I get when I'm working on a piece of artwork is there's a dialog and conversation between my, the medium and myself, and it's it's not able to be explained. Um, there's something transcendent and spiritual, um, that connects the work to where I am.

And I think that's that's the type of support system that is, uh, you can find that in people. You can find it in art exercise, but some way to tap into something that is bigger than yourself and, um, to connect in the process.

00:21:44.830 — 00:21:47.150 · Veronique Enos Kaefer

Doctor bloom does research support this?

00:21:47.190 — 00:21:48.790 · Dr. Bastiaan Bloem

Oh, there's so much to say.

00:21:50.110 — 00:23:48.890 · Dr. Bastiaan Bloem

I think what makes us human beings, human beings is connectedness. We are, you know, we we like to communicate with other people. That world are shrinking. And if you can't communicate because your voice becomes smaller and you can't communicate in a group, people think you're crazy. But there's a beautiful mind behind the masked face, right?

We call it behind the mask and behind the soft voice. So anything that brings people together, I think is essential. There the science is weaker. Although we know that, for example, group exercise you can exercise on your own, but if you do group exercise, you have to peer pressure. You know your mates are there, so you have to show up yourself as well.

But it also brings the social element to group boxing. The dancing is an example where human connectedness is intertwined with the exercise. And a quick word on mindfulness because supported by the Michael J. Fox Foundation, we are now studying whether mindfulness isn't just suppressing symptoms.

We think from animal work that chronic stress might harm dopaminergic neurons and thereby hasten disease progression. On a more positive note, if you dampen stress, you could slow down disease progression. So we're doing now brain scans before and after mindfulness to see if we can potentially slow down Parkinson's through mindfulness.

So just to encourage you and one quick thing because it is essential. Many people with Parkinson's, their symptoms started at a stressful period. And people think the stress caused by Parkinson's, and I want to take that moment to alleviate that concern. We published the paper and it was called The Straw That Broke the Camel's Back.

We described a woman who was burying her husband, and as the coffin was sinking down in the grave, her tremor started. Her doctor said that psychogenic. You don't ever go see a doctor for this. So we saw her ten years later, bad Parkinson's. And I said, oh, you're probably coming to see me. She said, no, no, I'm here for other reasons.

This is psychogenic.

00:23:50.770 — 00:24:16.250 · Dr. Bastiaan Bloem

We know that stress can unveil what was about to happen anyway. So if you are among the folks where stress, maybe you thought it caused your Parkinson's. It didn't. And I'm saying this because you've got many other things to worry about. Don't look back and regret the Parkinson's would have happened, unfortunately, anyway, and the stress just unveiled it.

But it just shows how important stress management is for people with Parkinson's.

00:24:16.570 — 00:24:24.440 · Lydia Anderson

Veronique then welcomed MGF Chief Scientist Brian Fisk to the stage for discussion on the latest Parkinson's research.

00:24:25.080 — 00:24:50.080 · Veronique Enos Kaefer

Now we get to dig in to the research behind better treatments and a cure. Brian. Hey, we have worked together for the 21 years that you've been here. It's been such a joy. It's been an ongoing kind of transformative journey. I feel like I can say this because I'm not a scientist, but I feel like everything we know now that may be the treatment of cure.

We didn't know when the foundation started. What have you witnessed in your tenure here?

00:24:50.120 — 00:25:35.870 · Brian Fiske

Well, one, I ran a marathon, actually, because of you. As you remember, we actually trained together for a marathon back in those early days when I started the foundation in the early 2000. You know, we were just really a few years old. We were, you know, I think still sort of getting on our feet, figuring out how the impact we could make.

At that time, there was, you know, some early drug development happening, you know, symptom improving type of approaches, some interesting trials that we thought might we're going to have more impact than they ended up having but genetics was just starting.

There was a lot of just things that were just feeling like they were just starting, just, you know, starting to show some glimmers of hope.

And now, you know, 20 years later, 25 years later, you look at these things and just the amount of progress that's happening. None of the progress has happened in the last five years. It's just been so exciting. And yeah, a lot of change.

00:25:35.870 — 00:25:45.870 · Veronique Enos Kaefer

What a ride. And we're still on it. Um, so we want a world free from Parkinson's. What does that mean and what will it take?

00:25:45.910 — 00:27:26.300 · Brian Fiske

So I think we all share that vision of what is a world free from Parkinson's and what, you know, when does that day going to happen? And, you know, for us as a research organization, it's important to think about, okay, what does that actually mean? What is you know, what has to happen, what has to be in place if we're going to live in a world free from Parkinson's?

And so, you know, when you think about that, you know, first of all, treatments, of course, we need better therapies. We need therapies that can address the, you know, the symptoms of the disease, obviously allow people to function better and sort of function in their daily lives. We, of course, want treatments that can also slow the disease down.

These so-called disease modifying therapies, the things that can target the biology and and hopefully slow the process of the disease itself. But that's not enough. You also need to be able to deliver that those medicines, those treatments, those interventions in a more precision sort of precise way, a personalized way.

We know enough about Parkinson's now, you know, even though people might share some symptoms, if you kind of look under the biology hood, there's a lot of biology going around, and we need to be better at being able to match those therapies to the right biology and the right people. So this idea of a precision or a personalized medicine approach also needs to exist in this sort of future world of a world free from Parkinson's.

And finally, and you heard, you know, boss, talk about this earlier, too. We know that it's not just about the stuff going on inside us, the biology. It's maybe, you know, turning inside an individual. There's this whole world we live in or living, breathing organisms, walking it around in an environment and being exposed to things all the time throughout our lives.

So there are and we know there are factors out there that can contribute, we think, to the to. To Parkinson's disease and related brain diseases. So if we can get rid of some of those things, we can also, I think, help, you know, ultimately get to this day of a world free from Parkinson's.

00:27:26.300 — 00:27:31.620 · Veronique Enos Kaefer

So we're working on it. We're doing well, I think, but but how well are we doing? How close are we?

00:27:31.660 — 00:29:51.000 · Brian Fiske

Yeah. So, you know, when I look sort of using that vision, you can kind of break it down and start thinking, okay, well, you know, what about treatments? Let's start there. How are we doing on treatments today? Are we getting closer? We definitely have a lot of treatments that are really good at helping to address some of the core movement problems in Parkinson's.

So you hear a lot about, you know, many of you are on dopamine medications, different types of dopamine medications. So we're getting really good at being able to optimize that sort of ability to just let people move and sort of function again. Over the last year alone, we had three new treatments that sort of different twists on how to deliver the levodopa medication.

The dopamine medication have been approved. So we're getting better at not only, you know, figuring out how to deliver it, make it sort of smoother throughout the day, but also make it last longer in the sense of, you know, as the disease progresses, we still want people to have that benefit. So how can we continue to extend the benefits of those drugs?

So we're getting really, really good at that. Of course we don't have there's a lot of other non movement symptoms that we wish we were better at treating. So there's still some more work to do there. And of course we don't have the disease slowing treatments yet either. So we obviously need to do some more work there.

So we're getting really good at I think, you know, we're seeing sort of this vision of what the treatment side looks like, precision medicine. That's an interesting one if you ask me. Five years ago I was like, oh, that's years away. We're not really there yet. But now in the last few years, we're really there's a lot of momentum, a lot of new tools that have been sort of discovered and developed a lot through the work of the Fox Foundation that are allowing us finally to start to sort of being able to look at the biology that people might have and start characterizing them by that biology.

We're taking a lot of lessons from the Alzheimer's field right now, because they're actually a few years ahead of us in the sense that they actually have some therapies that, you know, potentially slow the disease down a little bit. And they also have tools that can help identify people at risk. And so we're sort of looking at the work they're doing and seeing if that recipe might be relevant to Parkinson's.

So I think we're much closer to that idea now of actually a precision medicine approach as well. And we just need to continue to push work on that space. And then finally on the environment, you know, this is a tough one. There's, you know, lifestyle and other kinds of factors where, you know, we're dealing with some of it's modifiable.

Some of it's not really modifiable, but there's a lot more awareness around what's in the environment. Can we try to get rid of. And so when we think about pesticides and certain toxins so we know that awareness I think is also helping us to to get closer to that to that day.

00:29:52.080 — 00:30:24.550 · Veronique Enos Kaefer

The scope of what we're doing is truly amazing. When we do have an hour to sit and go through every category that might lead to a cure. I think it surprises people. We want better treatments than a cure for Parkinson's disease through a strategically run research agenda. But how are we organizing such a broad scope of, like, bird's eye view of an entire disease?

A favorite quote recently by one of our board members was the Michael J. Fox Foundation got together and organized the world's Parkinson's disease, and it really feels like that's true. So how are we organizing it?

00:30:24.590 — 00:32:23.220 · Brian Fiske

Yeah, yeah. I mean, you know, I mean, one of the things that was compelling to me when I first started the foundation early on was this, you know, in our mission statement, even back then, I just said, you know, we aggressively fund this research agenda. So I knew, you know, from the start, this this organization was really about, you know, driving that research agenda forward.

So what does that look like for us today? What does that research agenda look like? And how does it sort of again, inform that that that vision that we all have. You know, it's really around four big objectives that we have right now. So one, we really want to learn from this biological insight I was mentioning and really move that towards this idea of being able to have that better sort of clear diagnosis.

You can give somebody, so how can we take that biology and be able to say, here's what you have biologically, we know what you have biologically. We know what you can kind of expect from that biology over time, so that ultimately we can give you a clear sense of what you have and maybe what treatments could go for that.

So that idea of a clear diagnosis being a big first objective. Second, we want to take that biology. We really want to translate it into the sort of the language of drug development. We obviously want to turn that those ideas into therapies and sort of build kind of a better treatment pipelines. But you want treatments that are really reflective of the biology that's underlying your disease, and make sure that those are being developed and that those are well resourced and well supported to be to be tested in people with Parkinson's.

Third, we want to speed that process up so you can have these great ideas and these great drugs that get to clinical human testing stages. And it's just this slow process because it's just, you know, you're churning through. It's these take long time to set up the, you know, you don't have the right tools in place to really know if they're working or not.

And so it just feels like it's a multiyear challenge. So how can we speed that up? What's the work we can do to speed that up in different ways. And then finally, you kind of alluded to this already. How do we sort of work with the community? How do we sort of catalyze that community, get them focused on the right problems, advocate for the right issues, the right changes we want to see?

Get the research groups focus on the right research. So how do we kind of catalyze and connect that community being the fourth objective?

00:32:23.340 — 00:32:38.980 · Veronique Enos Kaefer

Okay. Let's talk about each pillar and unpack it a little bit. But like where it hits the road, what it looks like in actual research. Okay. So if I'm understanding the four pillars really are biology therapies, clinical trials and people.

00:32:39.020 — 00:32:40.860 · Brian Fiske

Yeah that's a good way to think about it. Yeah.

00:32:41.020 — 00:33:03.060 · Veronique Enos Kaefer

All right. So clear a disease diagnosis. And then that's linked to biology. And it seems like if we know the biology we're going to have better definitions of a disease and we're going to have better treatments that get to the core. So there's a lot in that phrase, a clear disease diagnosis, what's happened recently that's helping us understand the biology more, and what more do we want to do.

00:33:03.100 — 00:34:56.000 · Brian Fiske

Yeah. Yeah. So I mean, for many years, the last, you know, a couple of decades, a lot of that biology's been driven by sort of our understanding, particularly around the genetics of Parkinson's. And that doesn't mean that all of Parkinson's is driven by strong genetics. It just means that we by understanding forms of Parkinson's that are linked to genetic differences, we can start to understand and kind of unpack that biology and then start looking for that biology and even people who don't necessarily have those genetic changes.

So that has been revolutionary, and I think has driven a lot of our progress over the last 20 years. But, you know, our ability has always been stymied a bit because we haven't had an ability to actually kind of measure that biology in people while they're living. You can certainly look at it, you know, after someone passes away, you can, you know, look at, you know, tissues and sort of see the biology in the brain.

But obviously you want to do that when people are living. So the last few years, you know, this big breakthrough and having this new biomarker. So it's a biomarker. And everybody in this room has probably heard us talk about it. It's a it's a way of measuring a particular biology in Parkinson's, it's the alpha synuclein protein.

It's the protein that clumps in the brain of people with Parkinson's and we think contributes potentially to the disease process. And for years, we've never had an ability to detect that in people while they're alive. The last few years, the work that we've supported, we now actually have a tool that can detect that biology in the spinal fluid.

We're trying to get it out of the spinal fluid and detected in other places. But to have that tool now, we can now actually start to kind of categorize people by the biological form of Parkinson's that they have. So we know, for example, using that tool that a good majority of the people with the symptoms of Parkinson's actually are positive on that sort of that biomarker test, but some people are not.

And we before having that will we you know, we just assumed everybody had this sort of same Parkinson's biology. But now we can start to sort of categorize people by that biology and get to a much better, a clearer ability than to diagnose the disease.

00:34:56.320 — 00:34:59.400 · Veronique Enos Kaefer

Right. Better treatments. We know what that is. We want better treatments.

00:34:59.400 — 00:35:00.710 · Brian Fiske

Yeah. Better treatments. Yeah.

00:35:00.950 — 00:35:05.550 · Veronique Enos Kaefer

What are the disease modifying therapies? How's our pipeline? It's very robust. What does that mean?

00:35:05.590 — 00:37:56.090 · Brian Fiske

Yeah. So this is, you know, you know, for us, too, it's really about looking at, you know, the lens of how do we build that better treatment pipeline too. And so how do we take that biology, all that insight coming out of the genetics, all the other biological research is happening and sort of start to group those into biological pathways and say, okay, like can we make drugs, you know, targeting this biology or not?

Can we do it safely? What types of drugs, you know, is it you know, general? Is it pills? Is it gene therapy? You know, whatever it may be. And then how do we start moving that forward? So we have, you know, whole initiatives now that are really focused on sort of the first step of that, which is how do you kind of make sure that biology actually is targetable is translatable into therapies.

And so we have a lot of initiatives that are focused on getting teams together around the interesting biology that we think is relevant. And then actually, how do you funding the companies and the groups to actually develop and test those therapies? And so so we have a lot of work that's really focused on that right now.

So we the team also spends a lot of time looking at the current therapeutic pipelines. We think about 170 or so. Those are actually in human testing. So that's you know, you want stuff in human testing. That's kind of the ultimate goal for us to see those ideas make it to clinical trials. Um, about half of those we think are actually, you know, touching this idea of disease slowing.

So it's not just all symptom treatments that there actually are, you know, drugs that are trying to test for disease slowing as well. They represent a whole different range of biology. Some of them again, are, you know, importantly targeting that that protein, the alpha synuclein protein biology that we've talked about before.

Can we get rid of it? Can we remove it from the brain? And will that actually have an impact on disease slowing? Now with the new tool we have, we've been working with companies to see if that new tool can help, because obviously you can identify people who have that synuclein protein pathology is their form of Parkinson's, and make sure that those drugs are being matched to them.

So there's a lot of movement there. We've got some late stage drugs and human testing now targeting that biology, but a lot of other biology too, some of it driven by the genetic insight that we've been gleaning of other pathways, inflammation. There's a lot of interest right now. And understanding the role of inflammation might play in contributing to Parkinson's.

And so a lot of different therapies that are being tested in humans, targeting different aspects of the immune system and inflammation, um, maybe we'll talk about it later. Cell replacement is also an interesting this. When we first started, I think you remember there was a lot of interest in tissue transplants and other ways of replacing the dopamine cells.

Stem cells came around, and there was a lot of science that needed to happen first, before we can make stem cells safe enough to put in humans. Now we're seeing the fruits of that labor. A lot of cell replacement trials based on stem cells are now human testing, even late stage human testing. So there's just this robust, you know, like diverse pipeline that's really, really exciting to see so much.

00:37:56.130 — 00:38:07.090 · Veronique Enos Kaefer

It's encouraging. Write questions down about it. I need to talk more about the treatments. Um, faster, better clinical trials. How are we designing trials? Better. What sort of development tools are we using? Why go faster?

00:38:07.170 — 00:39:50.040 · Brian Fiske

Yeah. Yeah. Yeah. So so, you know, faster here probably, you know, want to make sure that we sort of, you know, define that better. It's not just that we don't want to run trials super fast. Like it's not quick and dirty. We're not trying to get to to to answers that we can't understand. It's really about getting to faster decisions, you know, good, clear, data backed decisions on whether a treatment is working or not.

And for us, that's really a couple of things. One, we need those measurement tools. So you know we obviously have the biomarker tool that's helping us not only sort of categorize and kind of diagnose the disease better, but we can use those tools in trials to to make sure that you're selecting the right participants to be in the right trial with the right drug, so that you're not going to have a lot of the sort of the extra noise that can happen when you bring people who don't have that biology into that trial, and they don't respond to the drug.

And you're like, oh, I guess my drug didn't work. I mean, that's, you know, that would be essentially a, you know, a false negative. You don't want that kind of research. You want to be able to actually know that the drug is targeting the right biology in the right people, so that you can get a clear answer.

So that's kind of one big major part of our effort around speeding up trials, which is developing those biomarker measurement tools, whether it's in bio fluids like blood or spinal fluid imaging, even getting better clinical scales. So the idea, you know, all of you know, the updrafts, this is the test you do when you go to the doctor, you know, touch your nose, you know, you get up on the chair, walk down the hall, things like that.

Those are pretty blunt instruments, right? You know, they're, you know, so they're not going to tell you really sort of your functional daily life type of function. So we need better scales as well to match to those other biomarkers. So a lot of our work is really focused on getting those better, more informative measurement tools so that we can get to those faster answers.

00:39:50.040 — 00:40:03.360 · Veronique Enos Kaefer

And then finally Yeah. Catalyzed community. It was always Michael's vision that we would do this. We would solve Parkinson's through scientists, business strategists and you, who are all of the people we're trying to catalyze.

00:40:03.400 — 00:41:11.030 · Brian Fiske

I mean, it's really everybody. Obviously, people living with Parkinson's. Of course, the research community, the clinician community, uh, government and, you know, policymakers, industry, you know, payers, the insurance companies who pay for the drugs. You know, all these people are important, critical components of this ecosystem, this community that we're trying to connect.

And we need the ball rolling in the right direction, right in the same direction, moving in the right sort of ways to address the problems that we see. And so the ways that we can do that, whether it's hosting events like this to educate and bring people together and make sure they're aware of the research that's happening, whether it is, you know, getting researchers focus on specific problems.

You know, we've been 15 years ago, we launched, you know, PMI, our our longitudinal cohort study of people living with Parkinson's. You know, that itself took a sort of casualization around the community to get people, not only the researchers together, but the the people living with Parkinson's, into the study industry to get buy in and start actually helping to sponsor and pay for the study.

You know, so a whole group of people that have to come together. So it's a huge, you know, huge effort.

00:41:11.070 — 00:41:12.190 · Veronique Enos Kaefer

Thank you Brian.

00:41:12.830 — 00:41:22.830 · Lydia Anderson

The day's last panel covered Parkinson's public policy, with MJFF patient council member Allie Signorelli and Chief Policy and Government Affairs Officer Dan Feehan.

00:41:23.670 — 00:41:27.070 · Veronique Enos Kaefer

Ali Signorelli and Dan Feehan, welcome.

00:41:27.230 — 00:41:28.070 · S10

Thank you.

00:41:28.390 — 00:42:07.500 · Veronique Enos Kaefer

Ali. How many of you know Ali already? She's she has 70,000 followers on her Instagram site I'm still Ali, where she talks candidly and honestly about what it's really like to live with PD. In your profession, you are a high level fundraiser. You are also a mom, a writer, a wife. You are a patient council member and we work together there.

You are the current moderator of the Foundation's PD IQ event. Um, you were diagnosed with Parkinson's in 2022. You were busy before. Why did you add all this? What does it do for you to be engaged?

00:42:07.540 — 00:42:09.820 · Allie Signorelli

I have a death wish. No kidding. People ask me this all the time. Oh, gosh, I'm so emotional already today. That moment when you hear the words that you have Parkinson's. Um, it is a.

Dark, dark feeling. And many people in this room have been through it, both personally or with their loved ones. You feel as though the floor falls out from underneath you. And this organization has been my lifeline since that moment. I tell the story all the time. But I came home from the hospital, crawled into my bed, turned off the lights, and watched.

Bravo for two weeks. Almost. Um. And my sister or my older sister sent me an email with a list and it said, get up. And the first thing on the list was get up, join the Michael J. Fox Foundation. And the first thing I did was sign up for the PMI study. And then the second thing I did was register for the Buddy network.

And it's just truly been a lifeline for me.

00:43:05.610 — 00:43:20.050 · Veronique Enos Kaefer

So we were so we're so glad you did. And we were all better for it. We need to know we need the face of Parkinson's to be very visible and accessible, because people can feel quite alone. And you, you help change that?

00:43:20.090 — 00:43:52.800 · Allie Signorelli

Yeah. I mean, I think most people, including myself and I worked in the brain health space. I was a brain health fundraiser for Alzheimer's for a decade. Um, I think most people assume that Parkinson's and Alzheimer's happen to other people, to older people. Um, and so when you're 43 and you have a muscle twitch and you think it's what my doctor called a benign nuisance, and then you find out instead it's an incurable neurodegenerative disease you're going to have for the rest of your life.

And it's a really frightening. Frightening place to be. But community has made it better for me.

00:43:52.840 — 00:44:25.680 · Veronique Enos Kaefer

Dan Feehan, you are our chief policy and government affairs officer. You've been a leader in public policy and politics, your lifelong public servant. And I love that phrase because it implies what it is. You serve the American citizens and the Parkinson's community. You have been engaged in ways that are both humble and bold.

You have been in military service, the Pentagon, federal campaigns. You ran your own strategy campaign. What drew you to public service and how did we get you? Why are you lending your energies now to Parkinson's?

00:44:29.200 — 00:44:35.240 · Dan Feehan

I think for me, it I could boil it down to a day. There was there was a single day that was. Nine over 11 for me. I was a college student in Washington, D.C., and I watched the Pentagon burn, and I made a decision that day. A decision to join the military, which would lead me to war, lead me to eventually a public school classroom, the Pentagon and beyond. But, um, it was a decision that was made years earlier through growing up with parents that showed me what public service meant, what it can look like, and a grandfather who had served in the military himself and for me as a kid, was larger than life.

Truly. Um, so my journey began on nine over 11, and that same grandfather also began a journey right around the same time. And it was a journey with Parkinson's. And I watched as over two decades, the disease took that that giant figure of a man and changed him and took from him. And eventually he succumbed to the disease just about five years ago.

And so I do this work with the same passion that I bring to public service, but with not just my grandfather and mine, but the many different Parkinson's patients I've met along the way, many of which served in the military themselves. And knowing that this work is not just fulfilling, but it is urgent. It is necessary.

And if not us, then then.

00:45:48.030 — 00:45:56.630 · Veronique Enos Kaefer

Dan and Ali. How are strong government partnerships essential to moving Parkinson's advocacy and research forward? Dan First.

00:45:57.510 — 00:45:58.230 · Dan Feehan

The Fox Foundation exists because not nearly enough was being done to attack and solve Parkinson's disease. We are in this room because that remains the case today, 25 years later. It's a very simple proposition, and in fact, the gap has only grown. The Fox Foundation years ago surpassed what our federal government does in terms of research dollars for Parkinson's.

And the gap continues to grow. And so we talk about this concept of a public private partnership. Partnership is only a partnership. If you are both putting effort forth and our government can do far, far more, it needs to do far, far more. But it won't just do it if if 25 years is not enough evidence, let me let me put it bluntly.

We have to make that happen. Advocacy is how you make that happen. Becoming a loud voice that is impossible to ignore is what galvanizes change. It is called advocacy and it is not waiting for Congress to go, well, maybe we'll do something more for Parkinson's. No. Is us demanding it? It's the patient community, the caregiver community demanding it.

It is essential. It is critical. And it's the only way that dynamic of partnership will change. So the basic research that our government has to fund is actually done so that the Fox Foundation can do the critical research that we do every single day.

00:47:17.580 — 00:48:54.720 · Allie Signorelli

Yeah. And I'll just crystallize that in some personal experience and numbers. Very well. I was, as I said, in Alzheimer's advocate and fundraiser, well before I was diagnosed, I was part of a team that helped implement Napa, which is the National Alzheimer's plan, similar to the National Parkinson's Project that was signed into law by President Obama in 2010.

Between 2010. 16 months after that, it became a plan. The National Alzheimer's Plan, which was sent to Congress that year. In 2010 or 2011, I guess Alzheimer's funding at NIH was $450 million a year in 2020. For funding at NIH for Alzheimer's research is $3.2 billion annually for Alzheimer's research.

That is because of advocacy organizations like this one, which the Alzheimer's, as Brian said, is a little further ahead of us. But we're loud, uncompromising, and unwilling to take the status quo as the answer to the problem of Alzheimer's. And I was on that team. I watched it happen. It was they were not superheroes.

They were just patients and families who said enough is enough. And that resulted in the first disease modifying drug for Alzheimer's. Truly, that is the path to the success. And the foundation has been doing that because our government hasn't. and it's not any one administration that can be blamed.

The National Parkinson's Plan was signed into law by Biden 16 months ago. Nothing has happened across two different administrations, so it's going to take loud voices like ours in this room to make that change happen. Um. It can. It definitely can.

00:48:54.920 — 00:49:12.440 · Veronique Enos Kaefer

So what you're alluding to, there's a lot of uncertainty in Washington. There's gridlock. Um, that can feel scary. We are not stopping. We're not pausing. How damn do we stay innovative and keep moving those policy priorities forward right now?

00:49:13.160 — 00:49:14.000 · Dan Feehan

Yeah, it can be exhausting. Terrifying. I do this for a living, and I find myself doom scrolling still every single week, because that's that's the reality of the day. But it is exactly times like this where we have to lean in that that is the dynamic of it right now. And the way you do that is by showing up, literally showing up, but showing up in every way, shape or form, led by patients led by caregivers.

This past September, the Parkinson's community had 275 patients. Their caregivers show up to Washington, D.C. over the course of three days. The Parkinson's Policy Forum was the largest gathering of the Parkinson's community in Washington in American history. That's what you do. You show up. We met with 40% of Congress over the span of two days.

It's incredibly impactful. And we came as a joint community along with Parkinson's Foundation, a PDA with a very central message around getting the federal government to fund $600 million. That is our $600 million a year for Parkinson's research. But you showed up. You lean into moments like this, and then you do it again.

We're coming back in March, so this is my first plug for any of you who weren't with us in Washington this past September. We're coming back in March, and we need you to be there. It is patient led. It is caregiver led. It has to be community led because that is what will move members of Congress to actually take action on this.

00:50:31.840 — 00:50:35.790 · Veronique Enos Kaefer

Ali, in moments like this, What helps you and other advocates avoid burnout?

00:50:36.750 — 00:50:37.430 · Allie Signorelli

You know, I think.

00:50:37.430 — 00:51:12.430 · S12

It's easy to get cynical and to be frustrated, especially in the climate that we're in today. But our lives are on the line, literally. I don't want my life to be about Parkinson's. None of us do. We don't want to be here. I would much rather be at my daughter's college football game right now watching them play, than I would be here.

Um, so I don't get the luxury of being burned out. Truthfully, I feel like I have a platform now, and I'm going to keep pushing forward until we get the cure, because my kids deserve that. So.

00:51:18.910 — 00:51:27.950 · Veronique Enos Kaefer

Thank you. So, Dan, we hear a lot about Congress and Washington, but there's more. There's other places where change can happen. What can we be doing right now in our own states?

00:51:28.270 — 00:51:46.500 · Dan Feehan

Yeah, states are maybe the most exciting thing happening. So as much as Washington, D.C. sucks, all the attention, the energy for things, really incredible things are happening in states for Parkinson's right now. Two weeks ago, the people of Texas voted to approve $3 billion in funding for brain racing. To be clear, that is 3 Billion more than all 50 states combined. Prior to that moment, states are stepping up. And importantly, this is work done by the Fox Foundation. We made sure that that funding would go towards not just dementia and Alzheimer's, but it includes Parkinson's. So that means $300 million a year for the next ten years will go towards brain research, and the Fox Foundation is going to make sure we steward and help guide where that money should go to.

Three nights ago, Governor Shapiro in the state of Pennsylvania signed a really complicated budget six months of fighting, but he signed a budget that put $5 million towards neurodegenerative research in the state of Pennsylvania that will come this next year in the state of New York. Right now, we're negotiating with Governor Hochul to include funding like that in her next budget in the state of Florida, as well. States are starting to step up and realize they, too, have a role to play in this because it is not just an American problem. It is a problem in their states. So again, second time, I'll call this out.

No matter where you live, Parkinson's can be advocated for in that state. And that's as simply as I can put it.

00:52:55.210 — 00:53:03.850 · Veronique Enos Kaefer

Okay. When we are building relationships with our elected officials, what are we asking for? What are the policies that have the best chance to move the needle for PD?

00:53:04.450 — 00:54:27.120 · Dan Feehan

We start with this idea of funding 600 million a year is not just it is. It is a balance in the partnership, but it is a statement that basic brain research is just as critical as the cutting edge research that the Fox Foundation does. Secondly, it's the idea of access to care. Parkinson's patient journey all look differently.

But, you know, many of the journeys that have taken years and years to arrive at a diagnosis. The idea that you might have a diagnosis, but you have to drive hours if you have any kind of access to care at all. The cost of that care doesn't match our health care system at all. Those are the very real things we are advocating for right now, that the federal government and state government can do something about it.

And while this doesn't matter as much if you have Parkinson's disease today, we cannot overlook the idea that it is the fastest growing neurodegenerative disease in the world. And in large part, we know that the environmental contributors to this play a huge, huge role. So the idea of paraquat, for example, an herbicide that we use in the United States all over the place, despite it being banned in 70 other countries and is a reality today, paraquat has a strong linkage to Parkinson's disease.

So this very idea of prevention so that this problem stops growing at the rate that it is, these are our core priorities right now. And these are things that you can advocate for right now by joining this community and becoming an advocate yourself.

00:54:27.160 — 00:54:32.680 · Veronique Enos Kaefer

Okay, last question for each of you, Ali Van Dam, what's one thing people in this room can do to help?

00:54:32.720 — 00:55:06.080 · Allie Signorelli

Advocacy is just storytelling. I think people get really wrapped around the axle of the term advocacy. They get nervous. They say, I don't know, I don't know how to talk to my member of Congress or, um, they get intimidated. It's just storytelling. Just go sit with a member of Congress or their staff. Truthfully, if you really want to know the truth, the staff members are the ones that really make things move.

So if you can get a meeting in your home state or on the Hill in Washington DC, just tell your story. Tell your story. And and they listen. And that matters when it comes to votes. So just don't be intimidated. I would say.

00:55:06.120 — 00:55:36.350 · Dan Feehan

Become an advocate. If you haven't met Amy Becker yet, she might have bothered you on the way in. Feel bothered you on the way out. You can become an advocate too. I will say this this movement is patient led. I mentioned the policy forum we did in September and we worked really hard to plan it. But the biggest takeaway I had was the reality that it is patient led, very first advocate I met well before we started meetings, introduced himself and said, hey, this is great, I already got started.

I said, what? What do you mean you already got started? The meetings don't start till tomorrow. He said, oh, I cornered my member of Congress on the plane on the way here, we got to work on the idea of cornering elected officials, but started that immediately. Then during the meetings, I get a call from Ali in the middle of the meetings, who has an idea that neither I nor all members of my staff had even considered around this? And lastly, my very last meeting, the 218th meeting of these.

Of these two days, I was exhausted, I was done, and I was I dared look ahead and go, oh great, I get some, maybe some time to myself. And the the delegation I was with from the state of Louisiana was in tears. Their last meeting had been canceled. And that happens. It happens on Capitol Hill, lots of moving parts.

And they were devastated because this was the one member of Congress. They wanted to make sure they had time with it. They had traveled a thousand miles to be there, and they didn't want to take no for an answer. And they said, can we, can we try to bother them? Can we try to make this meeting happen? And I looked at them and I said, it crystallize in that moment, if you can do one more meeting, then I can do one more meeting.

So we called the office, we came to the office, we banged on the door until they opened it up and they gave us a meeting, not just with staff, but with a member of Congress. So if you can do one more thing, then please join us with us. This is how this movement grows. Just doing one more thing at a time. That's how you can contribute to this.

00:56:55.500 — 00:56:57.740 · Veronique Enos Kaefer

Thank you. Wonderful conversation.

00:57:01.180 — 00:57:04.860 · Lydia Anderson

After the three panels, the speakers answered audience questions.

00:57:05.380 — 00:57:14.860 · Veronique Enos Kaefer

Brian may be boss. Um, are there alpha synuclein treatments that have moved forward and explain what that is for anyone who doesn't know?

00:57:14.860 — 00:58:10.130 · Dr. Bastiaan Bloem

So the alpha synuclein is the protein, as Brian was pointing out, that, uh, clotting in the brain. And we think that by preventing it from clotting or by removing clotted proteins, we can slow down disease progression. In all, fairness to trials have been fairly negative. I'm an author on the orchestra trial, which is going to be submitted to the New England Journal of Medicine literally any time.

Again, flat lines. Um, so that's disappointing. One of the drugs, Prasinocyma in a post-hoc analysis was showing a weak signal. There's a bit of debate among scientists whether such a post-hoc analysis has sufficient value. So that's moving forward to phase three trials. That's encouraging. I myself am a bit worried that we're tackling Parkinson's too late in that phase.

And I think that the anti alpha synuclein treatments may have to go to the prodromal phase, but there's still hope. It's not my number one bet. If I had to bet on a drug it wouldn't be an anti alpha synuclein.

00:58:10.370 — 00:59:11.000 · Brian Fiske

But it is a therapeutic hypothesis if you will, that needs to be tested, just like in Alzheimer's because Alzheimer's had lots of their early sort of their version of the protein is beta amyloid. It also sort of clots in the brain. I like that analogy and sort of how do you sort of get rid of those things? And, you know, after several trials, you know, they've finally identified some that seem to actually have some potential flowing of the disease, and those are the ones that are now approved in Alzheimer's disease.

So I think Parkinson's, we're still, I think, probably struggling through that. I think we need a really good solid test with the right drug to really show that and maybe also the right tools if we can get some of these new biomarker tools in there. So but exciting. I mean, for me, again, you know, this is for us.

We want to see these ideas tested in clinical trials. And even if they fail, which we all know is disappointing, it means that we're learning something about the disease and about the therapeutic approaches out there. So even if Roche's Phase three ends up failing, we'll learn something from that and we'll be able to use that to guide the next treatments.

00:59:11.440 — 00:59:18.160 · Veronique Enos Kaefer

How are researchers using AI to work more quickly to understand the disease? And more.

00:59:18.240 — 01:00:53.310 · Dr. Bastiaan Bloem

So. AI is going to revolutionize the world of healthcare in general. I mean, our lives in general, health care and the world of Parkinson's. We are very active, again, supported by the Michael J. Fox Foundation in using AI to develop wearable sensor signals. So what we do now in trials is we bring you folks to the clinic.

We test you and we say this is a zero or a two or a three, highly vulnerable. And then we bring you back a year late and say, oh, it's a bit better or it's a bit worse. You can already see how that's terrible. Now, a smartwatch or a smartphone can measure your symptoms objectively, qualitatively, in where it matters most in your own homes in real life.

But it cranks out terabytes of data. So we're using artificial intelligence to make sense of those digital signals so that we now have an objective thermometer, which is much more sensitive to see, for example, whether these disease modifying treatments are doing anything good. So I think that's an exciting area.

Another exciting area is that I talked about the growth of Parkinson's. There are fewer younger people with leaving school out for medicine. There was burnout among physicians, so that gap between the number of affected people and the young working force is growing and is going to cause a crisis anytime soon.

And AI could be a way out. For example, artificial intelligence, listening to the conversation between the doctor and the patient, automatically generating a summary in layman's terms so that you can take that home. So I think AI is here. It's here to stay, and it's going to have a huge impact on all of us.

01:00:53.590 — 01:01:43.940 · Brian Fiske

And it's important to you know, it feels like it's like the moment right now. Like we you know AI didn't exist until, you know, ChatGPT came along a year or so ago, but it's actually been around for a long time. This idea of machine learning is what we used to call it. It's essentially what AI is now. You know, I can remember some of the early research we funded way back in the day to, to understand protein biology for a particular protein, LR K-2, which is another protein linked to Parkinson's disease.

We're following millions of dollars at it, and all these people ate it for a number of years to try to better understand its structure, which is something that's helpful for drug development. And then AI came along in AlphaFold, which is this platform now that basically predicts the protein structure of every human protein out there.

And overnight they were like, oh yeah, there's the structure. So I mean, you know, it's like amazing what these technologies can do in this sort of advances. They can accelerate.

01:01:43.980 — 01:01:44.620 · Dr. Rachel Dolhun

And I think just On the Healthcare portion of it and also the personal portion of it, what we're seeing is what like you said, I think there are a lot of ways where AI can really help optimize care. Interestingly, we have to work with it and we have to help shape it. So in this, you know, where it can listen to your conversation and helpfully summarize to do better.

It was cutting out all of the side chatter, right? That's where we learn who you are as a person that you're going to travel, that it's really important that you are able to play with your grandkids. So we as doctors, as researchers, have to help shape this tool. And the other thing is, doctor, Google has been around for a long time.

Right. But now it's Doctor ChatGPT. And the difference here is that a lot of people are putting a lot of trust in whatever comes out from ChatGPT. I even see this from my family members who no longer come to me. They say I put all my medical records in there, and here's what it told me. And I have, you know, something that makes no sense.

So it's really important still to look at that information. Double check it with a credible source. It they say it hallucinates, right. It makes up things. So look at exactly what it's saying. Double check the sources. Take that to your doctor. Don't trust it. Don't accept it at face value.

01:03:00.410 — 01:03:14.240 · Veronique Enos Kaefer

Okay. Stem cells or cell replacement therapy? There's a few questions about that. Where are we? What role will that serve? Will it be curative or will it be like a dopamine replacement therapy. And how close are we? There were many questions, all right.

01:03:15.440 — 01:06:06.820 · Brian Fiske

Could jump in. So I mean, this idea of, you know, being able to replace the brain cells that are lost in Parkinson's, particularly the ones that produce dopamine, which which are really core to the movement components of Parkinson's disease. That idea has been around for for several decades now. I mean, and a powerful, you know, compelling idea.

Can we replace those cells in sort of give you back the function that you lost in the early days? We're using sort of tissue transplant approaches. Some of those felt like maybe they were working. But when we did some large trials, I'd say the community had large trials that the results were not unfortunately were not were not super positive stem cells came around.

This was sort of first isolated in humans and sort of shown to be potentially promising. The late 90s, early 2000. Um, we actually one of the first programs I got handed when I got to the foundation was actually a stem cell program. We gave a bunch of labs money to use different cell stem cell sources to see which ones could be potentially turned into replacement dopamine cells.

One of the first groups we actually funded was a researcher, Lauren Studer, at the Sloan-Kettering. He was one of the first people to actually demonstrate that you can generate what felt like a real dopamine producing cell from stem cells, you know, but that took a long time because we had basically learned a whole new biology.

We were basically trying to understand brain development, to figure out how to turn these cells into then a replacement cell. So that took a long time. Now, though, we actually have, you know, last count, I think, I don't know, I kind of like 10 or 15 groups, companies, some universities, some companies that are developing stem cell derived dopamine replacement therapy for Parkinson's disease.

And they're in human testing now. So I'm an early, you know, more sort of early safety studies. But at least one group now is in phase three testing with their approach. Now to answer your question like what is this going to mean if you know these continue to show some some promise. It's an interesting question.

20 years ago, you know, um, we thought they were going to have a lot more impact than they do. But now we are in a world where we have optimized levodopa therapy already. So even some of the newer delivery mechanisms that have been approved recently, we've got deep brain stimulation and sort of the more optimized now adaptive approaches for deep brain stimulation.

So we have a lot of approaches that can actually help restore a lot of that motor function. So the question will be, you know, we'll see what the data when they come out, how robust maybe these cell replacement therapies are. But they'll be entering a market now that I think will be very different from 20 years ago.

So it'll be interesting to see. How do you make that comparison? Do they need to be better than DBS? Do they need to offer some better safety or convenience or something like that. So I think more to come on that. But we're excited that we're finally going to get real again. Human clinical trial data to tell us help us answer these questions.

01:06:06.820 — 01:07:20.250 · Dr. Bastiaan Bloem

So a couple of quick additions. So one is stem cells are not a cure for Parkinson's. It's a way of bringing a little dopamine factory into your brain. And there it works like levodopa but in a more clever way. Second thing is, if you type stem cells and Parkinson's, you will find about 8.6 million hits where you can buy stem cells.

Don't. These are criminals. Yeah, yeah. I've had people selling their house to buy stem cells in Switzerland. Don't the statuses? There have been two back to back papers in nature recently showing that a stem cells, like a baby and a baby, can't decide to become a fireman or a doctor. The stem cell can decide to become hair, tooth bone or a dopamine cell.

So the good news is, if you transplant a stem cell into the brain, it decides to become a dopamine producing cell and not a tooth, which just does your brain. It sprouts to where it needs to sprout. It survives, not unimportant and carefully in phase one studies. That's the earliest. That's just looking at safety.

It was safe and there was a cautious improvement in symptoms. That's where we are. So we're going to move to phase two. Don't buy stem cells. Keep an eye open for research. And the Fox Foundation is your go to place to get the info.

01:07:20.490 — 01:07:39.930 · Veronique Enos Kaefer

All right. Question about care partnership Jon, Allie, do you have a mic close? This person is a care partner to someone who is their equal their partner. Um, they always want to be respectful. What do you need from your care partner? Um, as your Parkinson's progresses.

01:07:40.170 — 01:07:41.290 · Jon Nathanson

It's a good question. I think understanding and true compassion and understanding for for where I am and where people living with Parkinson's are, um, there's a lot of, um, there's a difference between compassion and helping. And, uh, I think helping is learned and people living with Parkinson's need to learn how to be more articulate about what they need and what they want from their care partners.

So it's a learning exercise.

01:08:12.410 — 01:08:13.130 · Veronique Enos Kaefer

Ali.

01:08:13.570 — 01:08:14.930 · Allie Signorelli

Well, I don't know. That's a good question. I have told this story many times, but Mike and I have known each other since we were three years old, so I don't deserve him. And I don't know that I need anything from him more than he's already given me as a true partner. I think looking forward, it'll shift and evolve over time, but right now he's basically just lifting me up and keeping me going.

01:08:33.569 — 01:09:10.160 · Dr. Bastiaan Bloem

Can I add one thing? Yeah. So I think it is time we start to say, I said, well, I'm no longer using the word patient. It's a person with Parkinson's. But I think we should be talking about families with Parkinson's. This is a disease that affects everyone your spouse, your children. We look after families with Parkinson's, and the one thing that always strikes me most is the care partners are doing amazing things, amazing things.

I don't think it's published, but the divorce rate is exceptionally low in Parkinson's, despite all the challenges, because the care partners deserve a statue with a horse and carriage.

But they do this because they certainly, in later stages, become a caregiver. And the one thing I want to tell the people is a, you know, you deserve the applause, but remain the spouse and not become the nurse of your loved one. And this is what I see a lot and that that really touches me.

01:09:36.680 — 01:11:26.380 · Dr. Rachel Dolhun

Yeah I've Spent the better half of the last year working on a guide for care partners, because it's a place where we historically haven't had as much resource and information. And I think one of the things you said the word invisible before, and I think a lot of care partners feel invisible when they're in visits.

We're focused on the person who is living with Parkinson's, and the care partner can often get left out. Or we're not asking, how are you doing? So speak up for yourself. But your partners. So just like us for understanding, they need your understanding to. And you need to feel empowered to say, this is what I need from you to best be your best care partner.

And the last thing I'll say is we always work with people in families who are living with Parkinson's, and care partners who can share their experiences, want to share their experiences, and we learn so much from that. But the top tip everyone gives us is talk. Like you were just saying, talk early, talk often.

And this was a real revelation for me because it's communication, right? And we all think we can communicate. I will say my my boss always I last about this because I say I went to medical school, I'm a doctor. Communication like how hard can it be? Communications. And I started in communications 11 years ago and it's really hard, right?

It's really hard. But you know I do. Communications on a broad level. But even the communications we have 1 to 1. How much is lost in those conversations when we're not aligned on what I need from the conversation, what I need from you in the conversation. So there's so much around that. And just like I was talking about with exercise really implementing it, that that's the goal with a guide like this is I don't want to just tell you to talk.

I want to tell you how to have those conversations and how to better communicate to be the best care partners to each other.

01:11:26.660 — 01:11:38.380 · Veronique Enos Kaefer

Thank you. Dan, I'm going to pull you in because why not? Um, there's also a question about can fair partners be an effective part of advocacy. Is their story worth hearing to?

01:11:38.460 — 01:12:32.930 · Dan Feehan

Absolutely. I think there's two ways, two ways of looking at it. Um, ultimately, any anytime you're having a conversation with with an elected official, you are one of maybe 30 meetings they're going to have that day. And so the goal for us when we talk about telling your stories, not just for the person with Parkinson's to tell their story, but the caregiver as well.

Because your goal is to have that elected official remembering that meeting when they go to bed at night, that's that's the goal. And that human story is what breaks through. But it also allows you to tell a different story, a policy story of Parkinson's. And it's the economic burden that this disease has on this country and throughout the world, much of it borne by the family itself, but is well borne by the taxpayer.

And it allows that story to have a level of depth that knows, oh, it's not just about the disease, it's it's those that immediately impacts in or around them as well.

01:12:33.250 — 01:12:46.650 · Veronique Enos Kaefer

All right, Rachel, I have a practical question. So we've been talking about there's been new FDA approvals of therapies. Um, what are you seeing there? What's available. Has it been beneficial. And Doctor Bloom as well, after Rachel?

01:12:46.770 — 01:15:03.070 · Dr. Rachel Dolhun

Brian, I think you mentioned in your panel that in the last year we've seen actually five new treatments for Parkinson's. Three of those are medications to our surgical procedures. So advancements in deep brain stimulation, advancements in focused ultrasound, everything that has been approved over the last year is an optimization or enhancement of existing therapies.

So new pills that that deliver levodopa in a better way, both immediate release that kicks in starts working right away. An extended release that lasts longer. And then there are two infusions. So under the skin continuous steady infusion of medication, both levodopa and then another one called apomorphine, which is a dopamine agonist.

Again all of these are existing therapies. And so we hear a lot from people. Well is this just more of the same. Are these just me two kind of therapies. And I say they're not for several reasons. One is all of these therapies are directed towards symptoms that happen with progressing Parkinson's. So as Parkinson's gets on five, ten plus years down and you get symptoms like off time where your medication isn't working as well and your symptoms come back, or motor fluctuations, which I call the roller coaster of Parkinson's, where your medicine works, you feel good, your symptoms are controlled, then your medicine wears off and you don't feel good.

And then take your medicine and you go on this roller coaster all day, every day. So the infusions can kind of help smooth those things out. The longer release of medication can help smooth that out. So there are more options for people with progressing Parkinson's. Most of them bypass the gut. We were talking earlier about how the gut slows in Parkinson's.

Constipation is a common problem. Your medicine doesn't work as well when you're constipated, so if we can bypass the gut, we get around some of those challenges. And then the third is what we were talking about earlier is it offers us more options to better tailor therapy to people. So not every medicine, not every therapy, not every surgery is going to work for every single person.

The more options we have, the more chance we have of better treating each person's symptoms.

01:15:03.310 — 01:15:20.310 · Veronique Enos Kaefer

All right. So while we're talking about treatments so these are symptomatic treatments that are available right now. Disease modifying treatments are something we want to. Bryan boss what are you most encouraged by in terms of disease modifying. And how long do we think that will take?

01:15:20.670 — 01:16:43.380 · Dr. Bastiaan Bloem

At the risk of sounding like a broken record. I think lifestyle is, I think, closest to delivering the promise of becoming a disease modifying treatment people have exercised in their life have a lower risk of developing the disease. I mentioned the sprouting of the brain following exercise. Does animal work to support this?

And then there's the challenge or the opportunity. We published a paper just two weeks ago in The Lancet Neurology. Go find it because it has practical recommendations. I publish on social media Parkinson Weekly, where I discuss that paper, how those different lifestyle interventions, if you combine them, may have additive or even synergistic effects.

So I put my money on non-pharmacological interventions. At the same time, I think it is a genuine time of hope. You know, we can't deliver a gold mountain where we can't, you know, deliver that. But I think it is a time of hope for people with Parkinson's. There are so many researchers working on the world.

I honestly think that from the time when I worked with Bill Langston until today, it is a different world today. And just making sure that the right treatments that you were mentioning, Rachel, are made accessible to everybody, is essential. We're not looking well after half the population of people with Parkinson's, because we treat women as if they are men, but they're not.

We're giving them male doses, which makes them more disconnected. We don't look at menstrual cycle, menopause. That's the message we should be telling.

01:16:48.010 — 01:16:48.890 · Brian Fiske

I agree.

01:16:48.890 — 01:16:50.210 · S13

A lot with what Bas said about the promise in the pipeline. I will say GLP one because we have a debate, but is, you know, I think it's interesting times. I've actually been sort of doing a lot of work on the foundation to try to better understand the impact of those drugs. I think it'll be interesting to understand whether everyone with Parkinson's might benefit.

01:17:08.250 — 01:17:14.210 · Veronique Enos Kaefer

Okay. Last moment. Rapid fire, each of you. What are you most hopeful about right now?

01:17:14.330 — 01:17:40.170 · Brian Fiske

I mean, I think just what we just talked about, I think in kind of what we alluded to before, I feel like, you know, we have we we have the tools in place, we have the plan in place, we have the motivation in place that we just need to get some more data on these things and really get clarity on them. And I think we'll start to really see these advances happening.

You know, I mentioned, you know, five years ago things felt very different. And look where we are today. So excited by all that.

01:17:40.370 — 01:17:57.770 · Dr. Bastiaan Bloem

It's hard to pick one thing. One of my lovely, lovely, lovely patients was an artist is an artist, and she drafted a cartoon of a pill box. And the pills contained not dopamine, but they contained. Hope. Amin. And that's what I want to share with you your dose of daily hope. I mean.

01:17:58.850 — 01:18:13.610 · Dr. Rachel Dolhun

It's the community. It's like you said, all the pieces are in place. And we quote Michael often for good reason. And he says when the cure is found and it will be, it will be because of all of us. So much inspiration and so much hope from each one of you.

01:18:13.770 — 01:18:32.210 · Jon Nathanson

I think that this community is is extraordinary, and the level of support and awareness that comes out of meetings like this is really important. I think we're all able to see things in a broader perspective and support each other, and I'm looking forward to a future of love and support.

01:18:32.250 — 01:18:32.810 · Veronique Enos Kaefer

Fantastic.

01:18:38.970 — 01:18:57.600 · Lydia Anderson

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01:19:02.280 — 01:19:17.240 · Veronique Enos Kaefer

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01:19:21.320 — 01:19:30.200 · Michael J. Fox

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