

Tiffany Robinson (00:02.356)

Welcome to ComForConnections, the podcast where science, care, and community meet. I'm your host, Tiffany Robinson, and today I'm honored to welcome Dr. Michael Okun, one of the world's foremost authorities on Parkinson's disease. Dr. Okun serves as the National Medical Advisor to the Parkinson's Foundation and directs the Norman Fixell Institute for Neurological Diseases at the University of Florida. He's also the co-author of a groundbreaking new book, The Parkinson's Plan,

A path to prevention and treatment, together we'll explore how families, caregivers, and clinicians can take powerful steps to prevent, slow, and manage Parkinson's disease. Dr. Okun, welcome to the podcast.

Michael Okun (00:45.6)

It's great to be here. Thanks for having us and thanks for talking Parkinson today.

Tiffany Robinson (00:50.454)

Absolutely. Dr. Okun, you've spent your career advancing treatment and care for people with Parkinson's. Can you share what drew you to this work and what led you to co-author the Parkinson's plan?

Michael Okun (01:03.66)

Yeah, so well, you know, first of all, we've been in the Parkinson space for a long time. And back in 2012, I had written a book called Parkinson's Treatment, 10 Secrets to a Happier Life. And it was a bit of a runaway bestseller. And in the prologue, I got myself into a little bit of hot water at the time for coining a phrase called the Parkinson pandemic. And in doing the research for that book, I became concerned that

the incidents and prevalence of Parkinson were growing out of control. And so when you think of the Greek words pan, which means all and demos, which means people, that's how you get the word pandemic. Now, before all these infectious disease pandemics, that was when the word was coined. And now we very rightly use it to describe things like COVID-19 and flu. But how about other things like degenerative conditions that are growing out of control? And so

After taking a lot of heat in 2012, Ray Dorsey, boss Bloom, Todd Scherer and I wrote a book called Ending Parkinson's Disease, has similar language to the new ending Parkinson's bill that just passed through Congress. And we showed the global burden of disease study numbers, estimating that there would be about 12 million, that's million with an M cases of Parkinson's disease by 2035. It's pretty incredible, right? And people said, oh my gosh.

Tiffany Robinson (02:22.019)

Wow.

Michael Okun (02:28.834)

That's nuts, but you all are still causing a lot of alarm. This is probably not true. Parkinson's can't be growing faster than Alzheimer's. And guess what? We just got another dose of statistics from the Global Burden of Disease Study, and we're already at 11.8 million in 2025. So we're about 10 years ahead of schedule on a schedule we don't want to be on. And we're growing faster than Alzheimer's disease and any other neurodegenerative condition. And so this is the reason that we're

really keen to draw attention and to get a plan before we have all of this suffering and we bankrupt our healthcare systems around the world. We really need to start paying attention and thinking about what we can do.

Tiffany Robinson (03:14.848)

Your book makes a bold case that Parkinson's isn't just treatable, it's also largely preventable, which is very exciting information because we hear a lot about slowing the progression, but I don't feel we hear as much about prevention. Before we dive into that, I'd love to acknowledge how public understanding of Parkinson's has shifted in large part thanks to people like Michael J. Fox, Ozzy Osbourne, Robin Williams. Their stories have brought this disease into public view.

They've also shown how different every Parkinson's journey can be. How do you think these public voices have shaped the conversation around prevention and care?

Michael Okun (03:55.148)

Yeah, so I think the public voices are super important and I love people stepping out and making a case. Let's talk about Ozzy Osbourne since he just recently passed away. He was very public. We wrote an op-ed here recently for MedPage Today talking about the courage that he had for speaking out and people actually identified with Ozzy Osbourne. They felt like he was one of them. He was one of the

The general population had that appeal. And he was very honest about his symptoms. He was honest that he went to Sweden and had a stem cell transplantation in a very good group, but wasn't sure whether it worked well or didn't work well. And so he shared that journey. And a lot of people have a lot of hope for a lot of these new treatments. And he helped people to stay safe with stem cell treatments by speaking out. And his family also spoke out about...

you know, being caregivers and the importance of caregiving and the burden that happens with caregivers. And so being public is so important because about a quarter of people with Parkinson's disease live with their diagnosis hidden. And if you've ever tried to live with anything hidden, it is a lot of stress. It's a lot of anxiety. There's a lot of stigma and it's needless stigma. And so I think Ozzy Osbourne really,

set a new message by being as public as he can, helping us to bring it down to it should be as your stigma, why should we have stigma that we have a disease like Parkinson's? And other people like Michael J. Fox, like Muhammad Ali, like other celebrities, Robin Williams with

dementia with Lewy bodies, people coming public helps a lot. But guess what? Our advocacy, as we point out in both the ending Parkinson's disease book and

The Parkinson's plan book is not enough. We have not reached the levels that we saw for polio. We've not reached the levels that people got to for HIV. And we certainly have not reached the levels we need for Parkinson to actually move the needle to get enough dollars, enough resources and enough awareness together that we can make a change. And so we really need to galvanize. so having people in the public eye like Michael J. Fox and

Michael Okun (06:11.19)
and others, it's super important.

Tiffany Robinson (06:14.53)

I actually had in my notes here today, I read your piece in MedPage today with the recent passing of Ozy Osborne. And one thing that you said is when public figures come forward like Ozy, more than 10 million people with the same condition feel less alone. I think that's huge. And we really owe them thanks for showing us a real example of what this disease looks like for them and their families. Another big thing that I took away from that piece is the perceived stigma.

and how that can affect not only your outcome, but your quality of life. Can you talk a little bit more about that perceived stigma that people feel?

Michael Okun (06:52.364)

Yeah, and you know that piece, the op-ed was co-written by Indy Superwoman. She and I have had a blog for many years called ParkinsonSecrets.com. And we also have a blog, the PDPlan.org, Radar CNI. And so she has been the leader in stigma and stigma research with a number of her colleagues in the literature. so, you know, in following her work and following the work of others,

It turns out that stigma is huge in Parkinson and people think, you just have Parkinson, but it turns out that everything that you do gets judged because it's such a visual of somebody living in society with a disability. One in five people actually don't have a tremor with Parkinson. So that's something that's interesting. have Parkinson's without tremor. Many people don't know that. And the non-motor symptoms, depression, anxiety,

and apathy, demoralization are much more disabling than what you can see. And so it turns out that people get picked on in their jobs, they get picked on at work, they get picked on and go to the grocery store, people think they're drunk, and this is just not acceptable. And when we look at society as a whole, we have to ask ourselves the question, should we be more tolerant of people that have neurodegenerative diseases and other diseases?

And why should there be a stigma on these folks? They should be able to lead their lives

normally in society, and we should all understand and help them to lead the best lives that they can. Currently, we're not set up to do that, and I think with awareness, we can get there.

Tiffany Robinson (08:34.948)

You have this tool in your new book called The Parkinson's 25. What inspired it and how can families start using it?

Michael Okun (08:35.522)

you

Michael Okun (08:44.11)

So the Parkinson 25 was really an outcropping from our last book, In Ending Parkinson's Disease, we learned lists were really important. And then even going back to the 10 secrets to a happier life, giving people specific things that they can do. And we asked the question in Parkinson's 25, that question is, what are you doing about your Parkinson and what are we doing as society, right? And so the Parkinson 25 is all about

the things that you can do that are actionable items that can either reduce your risk of Parkinson's or help you to live with Parkinson's better. And so for example, we now know they're one of the most viewed articles in the Journal of the American Medical Association Network over the last three months has been this article that Ray Dorsey, the co-author of the Parkinson's plan also co-wrote.

on golf courses and how close you live to a golf course, right? And people, all the golfers went, no, you know, this is not good, right? Well, it turns out that when you're close to places that spray a lot of pesticides, the pesticides get in the aquifer, that's our water supply. And then these chemicals like trichloroethylate, like pesticides that are sprayed on golf courses, dry cleaning chemicals, when they get into our aquifer, you can get exposed to them and that can...

dramatically increase your risk for degenerative diseases like Parkinson's disease. And so we think about the Parkinson's 25, we're gonna help people by helping people to make sure either they test their water or get a good water filter, making sure that their kids are playing in pesticide free zones, or at least with pesticides that are not toxic, neurologically toxic and don't cause cancer and those types of things.

point out that there are pesticides in certain wines. We talk about exercise, sleep, all of those things that are immediately actionable in one's life that we should be paying attention to that can make a difference, that can move that needle both for the person individually and also for society.

Tiffany Robinson (10:53.196)

One of the things I love most about this list is that a lot of the items on the list are easy. These aren't crazy items to follow. It's more about awareness of the things that I should be looking out

for. Can you share a few more items that are on the list that might be more considered? These are just easy things that you just wanna make sure that you're avoiding or using.

Michael Okun (10:53.614)

Thank

Michael Okun (11:17.87)

Yeah, so, you know, in terms of thinking about, you know, like everyday things, if you, I like to say it's kind of that garage test or that shelf test, you know, there are people that you walk into their garage and they have a herbicide called rotenone and rotenone is known to be associated with Parkinson's disease. So you don't want to be using that in your garden. And a lot of people garden, a lot of people do their own lawns. A lot of people are taking care of their own plants.

And we have a friend who is an old mentor of mine at Emory named Tim Greenemeier who's at Pittsburgh who's gone public with this story. And we tell this story in the book about how he actually discovered that rotenone could be used to make animal models of Parkinson's, which was enormously helpful in understanding both how Parkinson's progresses, how it affects certain areas of the cell, the muscle parts of the cell called the mitochondria, and then also how pesticides can be

really important to this story. And Tim Greenemeier himself tells his story in an important and high impact journal called Science of how he now has Parkinson's disease and the question about whether it was from his own exposure in the laboratory to this chemical rotenone, which appears in cabinets and in garages and things. so looking at what pesticides and what chemicals you have in your house is important.

If you get dry cleaning, take a look at your dry cleaning and see what they are using? Are they using trichloroethylene or perchloroethylene? A lot of dry cleaners are now switching to be more organic or use carbon dioxide or other techniques. And you always want to, when you get your dry cleaning back, take those bags off of it and let the dry cleaning air out. The biggest risk is for the people that work at the dry cleaning, but certainly you don't want to increase your risk by bringing those chemicals into your house.

Tiffany Robinson (13:12.398)

You've talked about how we don't necessarily have a great plan going forward on how to handle Parkinson's. Do you think some of this plan would be educating people on some of these risks that they could then kind of add to their day to day if I'm going to avoid these things, right? I'm gonna get a water filter. I'm gonna be making sure I'm cleaning my fruits and vegetables. Is part of that plan education?

Michael Okun (13:14.67)

So.

Michael Okun (13:39.382)

Yeah, absolutely. and, you know, I mean, education in a lot of ways is the most important thing, right? Awareness. If you're not aware of something, you can't appreciate it. So if you don't know there might be something in your water and you're thinking water issues are only Flint, Michigan, right? Or if you're allergic to lead or other things like that, or you see the fluoride, you know, know, controversies should be in should be out of your water and everything.

Tiffany Robinson (13:58.435)

Right.

Michael Okun (14:07.266)

you're not even thinking like, the water could cause cancer or increase my cancer risk or increase my Parkinson's risk. But if I just teach you that, I will tell you why I share some data. And when I practice medicine, I'm a clinician. So I go to the clinic and I see folks with Parkinson. I'm a neurologist by training, but I'm also a scientist who goes to the lab. And I tell folks every day I practice medicine, I know a little less. It's a humbling profession. 20 years ago,

Nobody was thinking about the environment and Parkinson's disease. Now we're all thinking about it. Second, if I ask you to do something or I suggest you do something, I never get mad at you if you don't do it, right? Just tell me what you did so I can learn from it because again, it's the practice of medicine. And when it comes to us making people aware, we just need to have those conversations, those dialogues, those deep dives and take a few minutes. And the office is so rushed. You're trying to get so many things done.

for an individual person with a disease these days. And what we need to do is we need to have these formative conversations where we're helping to educate people. Why? Why are we asking about your water? And once they go, and they have that aha moment, then they may say, OK, let me just make sure I've got a water filter on here. Or if I'm very concerned with where I live, we can have the authorities, the state or local authorities, check the water and see if there's anything in that water that we need to worry about.

We can ask the dry cleaner if we've been using dry cleaners for years, what do you use? How do you use it? How are you protecting me? And either switch or stop using dry cleaning. We can ask, you know, when we go onto a golf course, we can ask what days do you spray the golf course? Because I'd prefer not to have my round. I don't golf, but if I did, I'd prefer not to have my round on the days that they're spraying, right? And what do you spray? I think people should have a right to know. And by the way, the sites that are polluted all over the United States.

that are called Superfund sites. Many of them are not cleaned up. Most of them aren't. There are many sites that are just miles away from schools all over the United States. And they're not well marked. And people have a right to know. And we should be helping people to be more aware so they can appreciate the risks and they can make those choices themselves as to trying to make themselves safer. And hopefully we can leave this generation with less

Parkinson.

Michael Okun (16:29.09)

disease than the next generation with West Parkinson's disease and so on. And we can begin to curb that incidence now. Now people talk about the genetics of Parkinson's disease and it turns out that the Parkinson Foundation has a great study called PDGeneration. And in this study, they've been doing genotyping, which means checking the seven most common genes that cause Parkinson's disease. They've been doing it free of charge and they offer genetics counseling and just as a

way of disclosure, I've been their medical advisor for many years and it's a great organization. And it turns out that after all that data has come in, only 13 out of every 100 cases have a single Parkinson gene associated with it. So you know what that means? It means 87 out of every 100 don't. And so we better start looking at the environment and other causes of Parkinson disease, why it starts, why it progresses, how it progresses.

and understand this disease so we can begin to develop things beyond the genetics as to what's going on here. Why are we seeing this huge increase?

Tiffany Robinson (17:38.104)

Those numbers are shocking just how much your environmental conditions can be involved. I think education is key. At Comfort Care, we are so lucky. We have a dedicated team who researches and creates special programs that allow our caregivers to be better educated in different areas, such as Parkinson's. We recently, just a couple months ago, released our Parkinson's Pathway program to our caregivers.

With this in mind, how can home care providers like Comfort Care help reinforce some of these prevention habits and incorporate those into the day-to-day?

Michael Okun (18:17.836)

Yeah, so, you know, it's, it's, you know, one of those things that, you know, exercise is a good example, right? Exercise is a very powerful therapy for Parkinson. And people say, what exercise should I do? And I say, the exercise that you will do, right? And, so when you think about practicality, it's one thing to tell everybody to do something and to grow your parents, your father, your mother's finger and point at them and say, you need to do this, you need to do that. It's a whole other thing to have the conversation.

Tiffany Robinson (18:32.31)

rape

Michael Okun (18:46.304)

see them over time, try to integrate things into their lives that are gonna make a difference for them and are gonna be practical. So we know that, for example, people need to take a

multivitamin if you're taking dopamine. So that's practical. We can check on that every single time we see somebody. We know there's twice the risk of melanomas of the skin and twice the risk of thin bones in people. Even if you're a man, you get osteoporosis with Parkinson's. So we can check on those things. We can check those boxes.

make sure that we've ordered those things and had those folks seeing the appropriate people so they can be proactive in their care. But then when we start talking about exercise, we start talking about water, we start talking about exposure to chemicals, we start talking about diet, we start talking about food supply and washing your fruit, those can be more difficult things. I think what we need to do is we need to move the conversation to being more proactive.

so that as we're spending time in the clinic with people, as we're spending time in the rehab setting, we're actually talking about these things and checking them off the list and making them a higher priority to actually spend time with. And so we have to choose how we're gonna spend the minutes that we have with a person, both in the clinic, if you're a physician.

or an advanced practice provider, a healthcare worker, a physical occupational speech, swallow therapist, a dietician, we choose the minutes, right, that we have and we get to choose what we do during those minutes. And what Ray Dorsey and I are advocating for is that we actually spend more of those minutes talking about these things that are proactive and preventative and doing it on multiple visits over time. And that's the way we emphasize and help people to appreciate.

the importance of them. And then also when they come back and they're like, look, man, I can't exercise the amount that you're asking me to exercise because at XYZ I have a bad knee, I have a bad back, I just don't like it. And then you can start to think what are other alternatives we can do to help this person to succeed that are practical? Getting back to your question about the practicality.

Tiffany Robinson (20:59.778)

I really like how you are talking about education and making that something that you're working on, even across visits of just educating individuals so that they are aware of things that they can do in their day to day. You also just mentioned bone health. And one thing I hadn't seen talked about much before your book was bone health. What does a Parkinson's diagnosis have to do with bone health?

Michael Okun (21:00.611)

Thank

Michael Okun (21:23.596)

Yeah, so how about that, right? And so let me just back up and say this for anybody who's listening. Parkinson is not just a disease of the brain, and it's not just a disease of dopamine. Let me say that again. It's not just a disease of the brain, and it's not just a disease of dopamine,

right? And so if we start and help people to understand and appreciate that, they'll realize that Parkinson's affects your gastrointestinal tract.

Okay, we find the proteins that are associated with that degeneration in your gastrointestinal tract. That's like your intestines and your gut. And so it affects your poop, it affects your digestion, it affects your skin and your skin, the way that you sweat gets affected. And because of the way that you sweat and your skin is affected in some way that we don't understand yet, it puts you at risk for melanomas, right?

And because it affects the brain areas and the bone areas and also the areas that stimulate bone growth that are in your brain, but also your bones peripherally, we also get twice the risk of osteoporosis or bone thinning, even in men. And Parkinson's is more common in men than women. Women can get Parkinson's too, but we forget about the men. So a lot of women are getting bone scans anyway. Some aren't actually, because I ask everybody, I'm like, wow, you don't get a bone scan? You should get a bone scan anyway, because you're

a woman and then of course none of the men are getting bone scans. And so the relevance is that we see the pathways centrally in the brain and outside of the brain that implicate the skin, the bone and the organs. And so Parkinson's is a whole body disease and we've got to treat it.

Tiffany Robinson (23:07.652)

What are some support strategies that can help reduce injury risk at home?

Michael Okun (23:14.08)

So when we think about injury risk at home, I remember a recent person sent me a Ring doorbell video of themselves. And it was a horrible fall. And what happened was they bent down to pick up a package. You get a package from Amazon or UPS or FedEx or whoever your carrier of choice. They bent down to pick up the poor package and they tripped.

The package was heavy and they had a terrible fall, smashed their face, injured their hip. So when we think about safety in the house, this is why it's so important to be involved in physical occupational speech and swallow a multidisciplinary team at least once a year, if not more. Having personal trainers and we had also

Tiffany Robinson (23:47.637)

Ugh.

Michael Okun (24:09.494)

Talked about getting tax credits for people to get personal trainers to get counselors to get social workers to help to navigate like we have a cancer like we have an HIV getting that team around folks and Focusing on being proactive and I love the word proactive because we want to get out in front and we want to proactively prevent falling We want to help people to succeed in their home One of the ways we can do that is by ordering a home occupational therapy visit

where the occupational therapist actually goes out and makes the recommendations of ways that we can help to protect folks in their home. Also helping them to understand do's and don'ts, to understand things like, if you walk into a closed closet, folks with Parkinson's disease see the world as smaller than it is. They have trouble turning. They tend to fall when they turn. You're gonna turn. You're gonna need to pivot on a foot, pivoting on a foot like in basketball might be good for basketball. Michael Jordan, no offense, love Michael Jordan.

but it isn't good for Parkinson disease. You need a nice wide area to turn. so keeping people out of closets, closed spaces, opening spaces up, reducing the amount of furniture that you have, making sure they have the right assistive devices, and then reminding them in those small quarters, like kitchens, you know, where you're gonna turn and pivot on the island and everything, you have a tendency to fall. And sometimes the fall is actually worse when you catch your head or something else on the way down. And in the kitchen in particular, remember,

We make those kitchen floors hard on purpose so we can clean them. That's bad for Parkinson, right? And anything time that you reach and you reach higher than your shoulder level, okay, that also puts you off balance of trying to place things down where people can grab them easily, make it easier for them and keep them out of the situations that are going to promote falling, that are going to lead to fractures and lead to injuries.

and help people to be successful within their own house. Even for things as simple as in the modern world, a lot of packages now get delivered to the door. When I was a kid, packages didn't get delivered to the door. You went to the post office, right? It was different, right? It was a totally different world. Now, people are constantly going out, getting packages, which is great. You can get things delivered to your house, but that can place people at fall risk. So we have to teach people how to deal with that and how to become proactive and preventative.

Michael Okun (26:32.428)

We find it's very important to utilize both physical therapists and people should know the difference for movement, taking longer steps, using cues, getting the right assistive devices. Occupational therapists are so underrated and so important. And just a shout out to all occupational therapists and for people that don't know what OTs are, occupational therapists help you with all of those things you need to do every day, okay, to be successful in your life. And that could be.

different with different folks, everything from eating the dressing to getting packages from outside the door to having strategies, devices and proactive ways that you can succeed. So these things are super important.

Tiffany Robinson (27:12.812)

I like how you've said proactive and prevention. I agree. I think those things are key. Your book also emphasizes something that we care deeply about, Comfort Care, emotional and physical

support. So with our Parkinson's Pathway program, we help caregivers support not just the physical side of things like movement and medication, but also that emotional and behavioral side and those changes that we may see that come with the disease. I'd love to hear your perspective on

how care teams can support the whole person and their care partners through every stage of Parkinson's.

Michael Okun (27:47.374)

Yeah, well, first of all, a number of years ago, the largest real world study of Parkinson disease was done with the Parkinson's Foundation. And it was called the Parkinson Outcome Project or the QI project. And, in this project, we were interviewed. I remember doing an interview with the USA Today many years ago. And we talked about, as the data came out, the largest unmet need in Parkinson disease was mental health and particularly depression. Okay. And people don't really get that again.

They think it's just a disease of movement. They think it's just a disease of dopamine. So it's super, super important that we refocus people so that they understand that your quality of life is much more impacted with Parkinson's disease, with depression, with anxiety, with apathy. It is very common that people don't want to do things with Parkinson's, so helping to treat that apathy and also demoralization.

And you can get demoralized. I was in the clinic yesterday. saw two people that weren't depressed but were demoralized. You just start to get down sometimes when you have a disease like that. And you can help people through that. You just have to recognize the difference in what it is. All of these things that I mentioned are treatable. We have a crisis right now in the United States and around the world for a shortage of healthcare professionals. And we also tend to...

treat the things that we see and not the invisible things. And so super important for us to recognize these things, ask the question, do you have depression? Do you have anxiety? How are you sleeping? All of those things, absolutely critical. All of our therapists and our multidisciplinary therapists do an amazing job checking in on these things and actually reporting back. And the best thing you can hope for in the American healthcare system is a group of people taking care of you that are actually talking behind your back.

right? They're all talking to each other. You're hoping for that. And we don't get enough of that. And we call that multidisciplinary. And when they're actually sitting down and talking about you interdisciplinary. And so a lot of times you say, you know, this doesn't look right. Instead of it not looking right, let's do something about it. And one of the things that has been so amazing is over the years, we developed a system called Fast Track. We write about in the book for DBS surgical

Michael Okun (30:08.472)

therapies and how we began to learn how to develop these care systems better for Parkinson. This one was for people getting deep brain stimulation. And it turns out that all of the therapists, rehab therapists are very good at identifying things that are missed by other areas of the team. And it turns out that a lot of times they will pick up the mental health issues and sometimes the psychiatrist won't because again, there's a lot of stigma and people don't want to talk about these things.

A lot of folks with anxiety, if you give them an anxiety questionnaire, boom bang, guess what? They're gonna fill out zero, like they have no anxiety about anything. If you interview them, you ask them yourself with questions, you realize this person is about to burst. They have so much anxiety. And then men who present in their 50s, we've learned now, often present the first symptom is anxiety. Anxiety can be the first symptom of Parkinson. And so these are things that we have to pay attention to. Our therapists and rehab specialists are awesome.

We've got to improve our communication chain so that everybody's talking and then also have more social workers and more counseling therapists. These are not covered by Medicare. At the Fixel Institute at the University of Florida where I live and work for over 20 years, we pay for these through philanthropic. Very grateful patients helping other patients and other people with Parkinson's, which is awesome. But our health system should be paying for mental health.

social workers, navigators, like we do in cancer and HIV, to make things better and to create the right care teams. And so we are incredibly, incredibly grateful to all of our therapists and multidisciplinary therapists, including speech and swallow therapists, which I haven't mentioned. And we all need to talk to each other. And this is a problem with the way that our healthcare system is set up.

Tiffany Robinson (31:59.266)

I really like how you've talked about talking about mental health, it matters. And there is a stigma and sometimes people want to immediately say, no, that's not something I'm dealing with. That's not something that pertains to me. But I think the more we talk about it, the more people may see that it's okay if we're experiencing some of these symptoms and it's okay to talk to your clinician about it. And there is help available. I think that's huge. As we are coming to a close, I have a couple more questions for you.

The first one here is what's one myth about Parkinson's you would love to bust?

Michael Okun (32:34.754)

Yeah, so Parkinson's myths are super important to talk about. We talk about a number, Ray Dorsey and I, the co-authors, there's a number of myths. One is that Parkinson's disease is not treatable, and Parkinson's disease is Alzheimer's disease. And let me explain. We asked this way back when we published the 10 Secrets book, we were asking people, when you hear the diagnosis of Parkinson's, and you hear those words, you have Parkinson's disease, what does it

mean? Do you know where people's brains go?

They go to Alzheimer's. That's what they know, right? And so people actually equate, a common person will equate Parkinson's with Alzheimer's. How are they supposed to know the difference if you don't tell them the difference? Alzheimer's is way worse than Parkinson's, okay? All apologies to my colleagues and I see Alzheimer's folks too, okay? But it is a different disease, okay? And it's quite treatable, okay? And so that's the other myth. Parkinson's is very treatable.

And there's an old story that I like to tell that Matt Stern at the University of Pennsylvania taught me, and that's this story about the card reader. And a guy goes into the card reader, and she says, choose a card. And he chooses a card, and he turns it over, and it says Parkinson's disease. And the card reader says, she says, so you're going to get Parkinson's disease. We're all going to get something. You're going to get Parkinson's disease. Now, I'll let you put that card back in the deck and choose another card, but that's it.

Whatever you choose, you get. And the guy thinks about it and he's like, you know what? I think I'll stick with Parkinson's. Because Parkinson's is not Alzheimer's. It's not Lou Gehrig's disease. It's not a brain tumor, OK? It actually is quite treatable. There's a good prognosis for folks. And I have some folks with certain forms of Parkinson's that isn't one disease that'll go 20, 30, 40 years. I had one that was at year 27 yesterday and was asking people.

Is that your longest running? And I said, not even close, buddy. So keep going. Not everybody has mild forms of Parkinson's, but people should know that they do exist.

Tiffany Robinson (34:31.361)

You

Tiffany Robinson (34:40.408)

What's a policy change that you would like to see?

Michael Okun (34:44.236)

Yeah, so we think it's unacceptable that you can get HIV drugs for everybody. And then there are so many areas around the world that have no access to dopamine replacement therapy, which is a gold standard and really important for the treatment of Parkinson. So we believe that everybody should have dopamine. We call that out in our Parkinson plan in the book. There's no excuse that we don't do that.

We also would like to see the research funding go up. We put about \$250 million into Parkinson's, and that may sound like a lot, but it's actually just a little tiny bit. And what we need to be putting in is what we put in for HIV and other diseases that we've actually made a huge dent in and moved the needle. So we need to increase that by 10 or 15 times. We call for that increase in the book.

And in addition to that, we only spend two or three cents on every dollar on prevention. Why are we not talking about prevention of Parkinson's? We talk about prevention of cardiac disease. We should start preventing Parkinson. Why are we only spending two cents on every dollar for it? So we need a proportional increase, not only to get from 250 million to two to three billion, but also a proportional increase in what we're spending on preventative care.

Tiffany Robinson (36:05.124)

After Oaken, where can our listeners find your new book along with your other books on Parkinson's?

Michael Okun (36:11.458)

Well, first of all, all of our books, the proceeds go to charity and you can pre-order or order the book. It's available at PDPlan, PDPlan.org, PDPlan.org. On that website, you can go to Amazon or any of your book retailers should be able to order it for you and it'll be out on the shelves on August 19th, but it's already available for pre-order.

Tiffany Robinson (36:38.444)

Awesome. Dr. Okun, thank you so much for joining us today and sharing your knowledge with us.

Michael Okun (36:43.432)

It's been a pleasure and fun and important and happy to do it again.

Tiffany Robinson (36:49.602)

Awesome, thank you.