



**Live Well Today Webinar Series:  
Medical Myths and Parkinson's**  
Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello everybody. And welcome to Medical Myths and Parkinson's. My name is Melani Dizon. I'm the director of education at the Davis Phinney Foundation. And today I am here with Dr. Benzi Kluger. How are you doing Benzi?

Benzi Kluger, MD, MS, FAAN: (Professor of Neurology and Medicine, Director of the Palliative Care Research Center, University of Rochester Medical Center, New York):

Hi Mel, I'm doing great today.

Melani Dizon:

It's great to have you here. So, Benzi has been working he has a blog it's about medical myths. This is a big area of interest for him. Obviously, a lot of you have seen him, we've done a lot of palliative care work with Benzi. So that's also a big area interest for him. But today we're gonna be talking about medical myths, what to look out for, who to look out for, what is some of the language you need to pay attention to and so, we're gonna start out right now. Benzi, I just wanna know what is, you call it, and we're gonna say it for today because this is what you call it, it's medical bullshit. So, tell us about, what is that?

Benzi Kluger:

Yeah, I think you know, I think we can use the word bullshit, we're all adults here, and you know, we kind of know it when we smell it. But we don't always know it until after we step in it. You know, sometimes we have regrets and things will come up later. So, as I've talked about it and thought about it, you know, I would define it as when somebody claiming to care about your health sells you a product to help themselves, oftentimes help their wealth, without truly respecting your wellbeing. And there's various ways that could happen. So, there are, you know, kind of the classic quack or charlatan who is selling things purposefully to deceive people. There are, you know, certainly a number of gurus out there who have best-selling books and are, you know, very interested in promoting themselves and their fame.

There are people out there who are true believers who really believe in the things that they're pushing, but I would say that they're not respecting you because they are pushing things on you or recommending things on you that have never been tested or proven to be helpful for people. So, to me that feels disrespectful. And then there are also, and I think this is important that within the Western medical community, within doctors and surgeons, that there there's

definitely medical bullshit happening, so this is not something that's just an alternative medicine problem. Pharmaceutical companies have been guilty of this if we look at the opiate crisis. And if we look at some of the huge lawsuits that have happened around that, there were definitely deceptive practices that have cost people their lives. There have been a number of cases actually just in the New England Journal of Medicine of surgeons accepting kickbacks you know, of doctors who don't fully listen to you. So, this is really something where, you know, I feel like it's kind of across the board, you really need to be careful for people who are, you know, whether they're wearing a white coat, whether they're claiming to be a guru or they're selling a bestselling book who may not have your best interest in mind, despite their, you know, very promising claims.

Melani Dizon:

Right. Okay, great. So, I'd love to go back a little bit. If you could tell everybody you're a neurologist, you work in Rochester, but something sparked it for you. So, can you tell everybody, first of all, what do you do? What is your daily practice and where you're working at the University of Rochester, and then what was it that made you be like, you know, I have to start writing about this. I really have to do this.

Benzi Kluger:

Yeah, sure. So, I actually was from Colorado, and have done a lot with Davis Phinney Foundation, in part, because we cross paths a lot and, you know, hopefully we cross paths a lot more again, but moved here to Rochester recently, in part to start a neuropalliative care program. And just to talk about that briefly. So palliative care is a branch of medicine, and the goal of palliative care is to improve quality of life. And so, palliative care kind of goes outside of the traditional medical model to look at the difficult emotions that come up, to look at care partners, to look at planning for the future. A lot of the things that fall between the cracks and you know, up until about 10 years ago, you know, palliative care was very closely associated with cancer. And although it makes a lot of sense in the world of neurology and it makes a lot of sense for Parkinson's disease, it really wasn't part of care.

And so, you know, we've been growing by leaps and bounds and that's my life right now. But when I first started as a kind of a grown-up doctor after doing, you know, 25 years of training, you know, I hadn't really thought a lot about medical BS and this was before COVID. And I think now, you know, people are thinking about it a lot more, but at that time, you know, I thought this was just kind of a fringe thing and that it, you know, didn't really come up a lot. It didn't really affect a lot of people. It didn't really affect a lot of people who, you know, I cared to know. But what I found once I started listening to people, and once I got into practice was that it was happening a lot.

It was happening all the time and actually very intelligent people even doctors were oftentimes susceptible to it. You know, I think some of my early aha moments in the first year after getting into practice, one was, and I think we'll maybe talk about this more lately is stem cells for Parkinson's disease. And I had a few patients in Colorado who I dissuaded from doing stem cells. I had some patients in Colorado who I didn't dissuade from doing stem cells and went to Costa Rica or other places to get stem cell implants. And I bring that up as an issue because stem cells for Parkinson's, although they've been studied, there's no evidence that they're more helpful than placebo. And there has been a lot of research and actually a lot of concern of what's been called stem cell tourism, and people have gotten cancers from stem cells that were injected.

People have gotten cells that they don't really know where they're from. The concept behind it doesn't make a lot of sense, particularly if you're just injecting stem cells, willy nilly, and as I got deeper into it you know, I think some of the things that really kind of got me angry honestly, were where there were several New York time bestselling books. One was Grain Brain, which we might talk more about, the other was a cure for Alzheimer's disease that had a whole list of supplements. And both of these bestselling books had really no real evidence behind them. And yet you know, because they were best sellers because the authors were, were very convincing, because they offered a promise for a cure that no one else could offer, there was a lot of uptake and so it kind of struck me, I think two things at that time, one is that this was a really big problem.

And I think now that we're, you know, two years into COVID, I think we could all agree that that medical misinformation is a huge problem. But it was a huge problem before COVID, and it will be a huge problem, I think, you know, probably forever. If you look at the history of medicine, there's always been bullshit. But the other thing is that these things change all the time. And so, you know, the strategy of simply debunking one myth is not very fruitful because it'll be replaced you know, within a minute or a month or a year. And so really got me to thinking about, you know, how do we immunize people? How do we give people the skills to recognize bullshit, to advocate for themselves, and to do a better job of yeah, of avoiding things that would be potentially dangerous and are oftentimes expensive, but are very unlikely to help them as individuals.

Melani Dizon:

Right. Yeah. I think that, gosh, it's something where, you know, logically, you know, you might see something and say like, oh, this feels like a scam. And we think that we're gonna be really good in being able to identify something that's a scam, but when you put your emotions and your situation on the line, like a lot of that just logic kind of goes out the window and they're also, they're selling you this big promise. But for, you know, it doesn't work A, and we've known people, who've, you know, the debt that they've gone into trying to get these things, and then

not being able to afford the actual treatment that does do something. So that part's really tough. Like what are some of the telltale signs that people can look out for? Because I think what is important and I really hope people walk away from today is to once you have some tools, and once you have a few things that you can really, and we will share all of these real specific tips that Benzi shares with us today with everybody.

But once you have some of those, you're able to maybe take the emotion out of it. And when you see something, go to this checklist and say, does it cross any of these off? And maybe I need to look at it a different way. So, what are some of the signs?

Benzi Kluger:

Yeah, so I kind of, you know when I'm thinking about, you know, kind of the cure for bullshit, one of the things that I would say is kind of developing an ability to see with the eyes of a skeptic. So, you wanna take a look at things skeptically and I've made and actually in the Davis Phinney Foundation victory book in the appendix there's a list, so, you can also go there to find these steps. But one of the things that I created there was kind of a detector. So, these are things, and I think once you read through the list, they'll make a lot of sense. And what I've actually found from talking to family, friends and patients is that after they've read the bullshit detector, that they really are seeing in a lot of places where they didn't see bullshit before. So, I would, you know, we could kind of divide them into a few categories. So, one of those would be unbelievable hype, you know, and I think the word unbelievable you know, is telling you exactly what it means that you shouldn't believe this. So, you know, it's unbelievable that somebody's able to cure Parkinson's disease by a change in their diet. And yeah, it is unbelievable, you know? So, when you see certain words revolutionary, miraculous, game-changing...

Melani Dizon:

Never before seen...

Benzi Kluger:

Yeah. So, all of those things you know, should be tip offs that you may want to you know, look at it with greater scrutiny. You shouldn't just accept something unbelievable or a game changer on the face of it. A second thing is that the information provided is clearly tied to selling a product. You know, whether that be buying a book, whether that be buying very frequently buying supplements and I can tell you right now that there is no evidence behind you know, practically any supplement for Parkinson's disease. So, when people have a complex list of supplements and they're the people who sell it to you, and they're telling you that they have the cure for Parkinson's and you wanna be skeptical.

Melani Dizon:

So, there's truly like, no, there has not been any evidence based that any, I mean, obviously they're not gonna cure it, but that there's no science that supports the need to buy hundreds of dollars every month of supplements.

Benzi Kluger:

Yeah. There's been you know, there's actually been large studies of vitamin E and enzyme Q1. So various vitamins that have been negative studies there have been a host of animal models looking at various supplements that haven't gone forward to human trials. And I think with the exception of melatonin, which we might talk about later you know, there really haven't been well designed tests in people and just to skip ahead in terms of my take on a lot of these things that if somebody wants to, for example, add coconut oil to their diet on the basis of an article, if there is no evidence behind it, then I say, you know, let's take a look at the risks, let's take a look at the cost. Does this make sense to you?

If this is something that you wanna do, you know, I'm not gonna stand in people's way from doing things that if it makes sense to them as long as it's safe and looks you know, is relatively inexpensive, but when you get into some of these things that are costing hundreds or thousands of dollars a month then I kind of get a little bit more angry and will, you know be a little bit more opinionated in terms of letting people know that, you know, I really think that this person who's selling you, this is trying to make a quick buck off of people who are in a desperate situation. So, those are, you know, the other thing that I think is really a telltale sign is that all the information is found at a single website is coming from a single person.

One of the hallmarks of good science is that things are replicable, meaning that if I do an experiment here in Rochester, that somebody in Boulder and somebody in San Francisco would get the same results. And if you look at something like levodopa and you do randomized trials, like levodopa works no matter where you look. If you look at other things, as an example, one of the best-selling supplements for Alzheimer's disease is something called Prevagen, which claims to be evidence based. There's been only a single study done of Prevagen, and that was done by the people who own the company that makes Prevagen. It's never been replicated. There's nobody else in the world that I know of who is excited about it with, you know, potential exceptions of maybe amazon.com who's selling it and other people but there's no one in the scientific community who's very excited about it.

I mean, so those are some tip offs that you're dealing with unbelievable hype. There's also unreliable experts and there are a number of people. And I think, again, one of the tip offs just like unbelievable hype is when people refer to themselves as a medical expert that's always, again, something that maybe should catch your attention. People, you know, oftentimes don't have the right credentials for what they're claiming to do. I think the most famous example of this is Linus Pauling, who was a Nobel prize winning physicist and has done undeniably great

science, and yet was promoting very high doses of vitamin C with no science behind it. And really actually brought some discredit to his name you know, through that work. But, you know, there's tons of books out there by PhDs or there's doctors who have no knowledge of nutrition who are writing books on nutrition. So, people don't have the right knowledge or training.

Melani Dizon:

Yeah. I actually wanna just click on that a second, because I think that is one of the things that's actually the most difficult to spot because right, we're sort of trained that this person is a medical doctor, they're a PhD, for this, that, and the other thing, and, you know, Parkinson's experts as well, and it's really important that when you're looking for a doctor that you are doing as much research on that person as you possibly can, because just because it has MD next to their name or PhD next to their name, it doesn't mean that everything they say is right. And so, it's harder to spot because we want to trust that, but it is possible right to come across people that, oh, well, this is my doctor, but actually I didn't realize they have a whole internet presence where their whole thing is selling supplements or doing, you know, this, that, or the other. So that's an important thing to know about.

Benzi Kluger:

Yeah, absolutely. And there are an increasing number of people who are you know, sometimes call themselves functional neurologists or functional doctors or things like that who subscribe to something that's really not mainstream, that's not evidence based. And you do have to be careful. And there are also an increasing number of people who in the United States, even who you know, promote stem cells and you know, in the world of DBS you know, I think there's, you know, sometimes financial gains that drive people's recommendations. You know, and I think that that would tie into some of the other things I would say about unreliable experts is that if people don't want you to get a second opinion, don't want you to look elsewhere, use fear as a tactic to try to get you to go along with their treatments. Tell you things are too complicated to explain. You know, all of those are kind of subtle clues. They're not treating with your respect and they're playing and preying on your emotions to get you to go along with them. That's not something that, you know, you really want in somebody that you're trusting with your life and trusting with your care.

Melani Dizon:

Yeah. I was talking to a doctor not too long ago and the claim was we're the only people with this information. And I was like, well, that's like a nail in the coffin in my book, like when something is coming and it's great, like you share it with everybody, you want the medical community to know about it, nobody's holding onto it as this, I mean, if it's a patent drug fine, but like, you know, something else that's not a good sign.

Benzi Kluger:



No, it isn't. Yeah. I mean, and, you know, some medical experts you know again, feel like the medical community they'll play on that. They'll say, you know, the medical community is against them because they don't wanna see Parkinson's cured and I have to operate outside the US. And, you know, all those things are gonna be clues. You know, again, if you look at it with the right lens that maybe this person is not, doesn't have my best interest in mind, maybe they're really looking out for themselves.

Melani Dizon:

Right. Okay. Really quickly before we move on, everyone wants to know what your t-shirt says.

Benzi Kluger:

Oh yeah. And this is a shirt I did wear purposefully for this.

Melani Dizon:

Oh, look at that.

Benzi Kluger:

So, it says to be scientifically literate is to empower yourself to be able to know when someone else is full of shit.

Melani Dizon:

Okay. Are you selling those?

Benzi Kluger:

I am not actually. It's from oh, shoot, the guy from the New York Natural History Museum skipping out on his name...

Melani Dizon:

Okay. We'll do some digging. We'll find it for everybody.

Benzi Kluger:

But anyway, so yeah, I did wear that purposefully today. So, then the last kind of group of things for the bullshit detector is unproven products. And again, these things, when you're looking at them in the right lens, give themselves away. So, if something is good for everything that's pretty good sign that it's good for nothing. Because if you think about it you know, people don't have you know, Parkinson's is not caused by the same thing as Alzheimer's, is not caused by the same thing as cancer. And so, when you have the same product that's claiming to cure everything that should always make you a bit skeptical. Similarly, if something is claiming to be a hundred percent safe should make you wonder. You know, if you don't have any side effects, then they're most likely you don't have any effect either. So, you know, placebos are great and

people, you know, can sell, in fact, a lot of the things on the market, a lot of supplements are placebo and, you know, they don't have a lot in the way of side effects, but they also don't have much in the way of real effects. If products are unregulated, you have to definitely be very careful about that. And I think that's true actually, unfortunately, for the whole supplement market.

Melani Dizon:

Yeah. Can you actually talk about that in a little more depth? Like for people that are looking at supplements and maybe their doctors prescribing it, like, what does it mean that it's not regulated and why is this important and compare it to something that is highly regulated that they might take for Parkinson's and...

Benzi Kluger:

Yeah. Well, I mean, I think this is actually a telling story of you know, kind of, you know, I think a theme here is kind of follow the money. But if you go back, I think it was actually in the early 1990s there was a quote grassroots campaign, really an Astro turf campaign led by GMP who makes natural supplement, or sorry GNC, general nutrition centers that makes natural supplements to keep the FDA out of our supplements and it was successful and they, you know, had a lot of letters and so it's unregulated. And what that means is that people, you know, would be able to print whatever they wanted to on bottles, as far as making claims for what this cures or does, what's in it, and you know, while on the one hand, you know, I guess you can kind of respect that desire, but if you kind of fast forward, the New York attorney general you know, did some investigations and for a lot of GNC products, there was nothing in them except for rice flour and sometimes house plants. And so, you know, no regulations means you don't know what's in the supplement and there've been a ton of studies, you know, cannabis actually is also maybe surprising to people unregulated.

Melani Dizon:

Yeah. We're gonna definitely talk about that topic for sure. And I think the, I guess the big question around supplements is if it's unregulated and they've said, okay, well, you know, there's nothing that's gonna be bad. Nothing bad is gonna happen, but can something bad happen, I guess, is like the bigger issue. Have you experienced that where, you know, somebody is taking a supplement and it's actually causing harm? So how do they get away with that first of all, and what can somebody, you know, do when they're looking at it?

Benzi Kluger:

Yeah, the fact that it's unregulated obviously makes it harder because there's not a process for it, you know, so ways that people get hurt is one, and there have been some infamous cases of supplements and particularly from India that have been found to contain heavy metals and arsenic. So known poisons. There have been quote natural supplements in many cases from



China that have contained known pharmaceuticals. So, all-natural sexual booster that's found to contain Viagra.

Melani Dizon:

Yeah. My father-in-law took one of those for his like prostate cancer and it just absolutely, I mean, it was terrible.

Benzi Kluger:

Yeah. So those, you know, and for things that do have side effects they can interact with other medications. So, cannabis can, things can slow down metabolism. They can have interactions with other medications. You know, sometimes people will stop taking medications at work in favor of supplements. So that's the way that people can be harmed. With cannabis, I was about to say, because it's unregulated that the levels of CBD and THC can vary markedly you know, from product to product and from dispensary to dispensary, despite what's on the bottle and that's been studied, but, you know, people may get something at one dispensary, they do fine. They get something that says the same thing on the label from another dispensary and have a very adverse effect. And so they're, you know, not to say that, you know, all supplements or vitamins are bad and there are things that are regulated, but, you know, it is definitely very much a buyer beware kind of a market.

Melani Dizon:

Yeah. Okay, great. I think you were still, let's see, I think you were going down the list of what to look out for, with products and supplements.

Benzi Kluger:

Yeah. And I guess I would say the couple other things with products and then actually one other thing to say with hype. So, with products, and this gets a little bit deeper into science is that you oftentimes products will rely a lot on what's called anecdotal evidence or expert opinion. And so, what anecdotal evidence means, it's basically like a rumor, but anecdotal evidence means that somebody somewhere said that it helped them. And if you go to a website or you see on a product, and there's a whole bunch of quotes, and there's not a lot of data or studies, that's you know, not a good sign. Expert opinion, again, oftentimes the experts who they're quoting get a kickback or have some other benefit from recommending it.

And that's very true with New York times bestsellers, as you can actually see, there's almost like a circuit of people whose names are on a lot of books and it's not accidental and it's not because they're experts, it's because they're helping their friends sell their books and they're selling their own books. So, those are, you know, things that come up. And then I would say the last thing that comes up unfortunately frequently is that the media and I'm talking really about mainstream media will, I think to sell ads, you know, oftentimes blows things up out of

proportion. So, there's you know, you never see a headline that says you know, new Parkinson's study suggests that this might be helpful some of the time for some people. It's always, you know, game changing cure coming from the University of Colorado. And I can't tell you how many times, you know, Parkinson's has been cured in mice and cancer has been cured in mice. But when you dig deeper into it and you look at the actual study it's very often, it's a mouse study, it's a cell study. It's something called an epidemiological study where they might find an association, but all of these things fall very short of actually proving anything.

Melani Dizon:

Yeah. Can we talk, can you talk a little bit about that? So, there's sort of a progress and I'd love for the community to hear a little bit more about that process of research and how it often it starts with like, you know, initial research and then different phases and how most of these never get past that initial phase.

Benzi Kluger:

Yeah. I can give an example actually, before I got into neurology, I was working in a nutrition lab and part of the reason I was working in a nutrition lab is I, you know, I kind of like being outside of the box. I thought that there was great promise in nutrition. And I thought that, you know, maybe this was a way that people could take less medications and drugs and yeah, so anyway, while I was working in a nutrition lab, there was a kind of a shocking study that came out, which was you know, I think we all feel like vitamins are good. You know, most people would not argue with that. And so, there were a bunch of animal studies suggesting that vitamin A might prevent or slow lung cancer. And there were also some public health studies that suggested that people with higher levels of vitamin A in their blood or taking with higher levels of vitamin A in their diet may have a lower risk of lung cancer.

And so that all looked reasonable. And so, the NIH went ahead and sponsored a large trial testing, whether vitamin A or vitamin E supplementations would you know, cure or prevent lung cancer in smokers who were at high risk for lung cancer and what they found and what was shocking, was that people getting vitamin A supplementations actually had worse cancer and a higher rate of cancer. And so it, you know, two things, one, it goes to show you that, you know, things that you think may be safe may not be that safe, two is that you really honestly don't want to, you know, you definitely don't wanna put your life on the line based on studies that were not well designed studies to test the efficacy and safety of things. There's a whole bunch of ways that things can be as associated.

You know, one example that I've given a talk, is that there's an association between people eating ice cream and shark attacks. You know, both of those things happen. There's a third factor there, which is that shark attacks and ice cream consumption both go up in the summer when people are at the beach. But nonetheless, you can graph it. And there's a very strong

correlation between those two things. You know, I think in the case of vitamin A in the diet that, it could be people who eat more vegetables are also less likely to smoke. So, there's a number of reasons why you see these associations. Nonetheless, if you read the news and you can drive yourself crazy doing this, there's a new thing that you should or shouldn't eat every single week. Yeah. And it's always based on a single paper and it's not done based on a well-done study, but that's not what sells newspapers.

You know, what sells newspapers is that coconut oil is a game changer for Alzheimer's. Whatever the story is of the week. And so, even, you know, reading, well-established news reporters, newspapers, you have to take it with a grain of salt and some skepticism. And if you're really interested in it, you know, nine times out of 10, if you dig one layer deeper, you can see right through it. And you can say, oh, this is really nothing to get excited about. Maybe in 20 years we'll do this, but more likely we won't, we'll forget about it.

Melani Dizon:

Right, right. I just wanna answer these two questions from the chat real quick. And then for those of you, who've asked specific about a specific item. We're gonna get to most of those. But Don said, has DP, I'm assuming DPF ever published a list of purveyors or supplements that have no effect or are harmful to people with Parkinson's? We do not post a list of something like that, and we actually don't post any supplements because just like Dr. Kluger said, there's no evidence that these are going to be helpful to people with Parkinson's. So that's not something that we promote or publish in any way. And then Lisa, hi Lisa, great to see you Lisa Cohen, there is a difference between published research and a press release, released from the entity where the research was conducted. Can you please speak to that?

Benzi Kluger:

Yeah, and in fact, you will see pretty frequently, this is another sort, I can't tell you how many times I get emails from patients or friends or family. You know, that every University is promoting their researchers. And so there there's press releases from Stanford, from UCSF, from Colorado. And again, the motive there, and this is, again, it's always about following the money. You know, the motive there is they wanna get philanthropy, they wanna get donors, they wanna get people excited about research at their institution. And so again, things are blown up. And as the question says, I mean, there's a very big difference between those writeups, between news writeups, and what you would actually see in a journal. And sometimes the discrepancy, I was involved in, it was about 10 years ago, that there was some work being done at the University of Colorado, which was good science.

And they were looking at the effects of microglia, which is an inflammatory cell in the brain and how that might be involved with Parkinson's. And they interviewed me as an expert in Parkinson's, and I did my best I thought to make the point that this was you know, a limited

study, it was done on cells. Yes, it looks, you know, it looks promising, it looks interesting, but it's in no way, you know, to be conclusive. And after they got done editing and cutting things it became a, you know, a pretty sensational story and they didn't use very much of my interview. But you know, and I got actually frustrated towards the end of it, because it was clear that this woman came into the interview with a story in mind and I didn't wanna go along with her story. She was gonna keep asking me questions until she had enough things to make that story happen. But that story was very different than the original papers, which were, you know, I think, interesting to me, I don't think they'd be interesting to as many people as the, you know, researchers in Boulder cured Parkinson's disease.

Melani Dizon:

Right, right. Well, and also like, you know, when you think about the press releases, there's nothing wrong with wanting to bring attention to the researchers and to get funding for research, and we're not saying that there is right, we're just saying, do your due diligence, look beyond that press release, look to the actual study, go to the clinical trial, see what they're doing, see what their methodology is, see what they're testing and then follow that because you gotta go to the primary source and that's not, the press release is not the primary source. This is a great question, waiting for this question the whole time. So, thank you Kelly, for asking it. With the true eyes of a skeptic, why should I believe that what you say is any more valid than any other statement about supplements or treatments?

Benzi Kluger:

Yeah. You shouldn't.

Melani Dizon:

Right. That's the whole point.

Benzi Kluger:

And I think, one of the points I've made in my blog, and it is actually part of a, you know, book I'm working towards is kind of this idea of what I would call the expertocracy. And I think that we live in a society actually where we're increasingly asked to trust experts. And sometimes there's a, you know, and I don't think the pushback against that is necessarily a bad thing, you know, but you need a pushback against it the right way. And so, I think when people don't understand science, when they don't understand medical literature, when they don't understand research then they put themselves at risk to you know, be victims of pseudo experts. And so that's really, anything I say here, you should think about it yourself, see if it makes sense for you.

You know, I definitely don't want to put myself as a new guru. You know, that's not my goal at the end of the day. My goal at the end of the day is that you become your own guru. And I

guess I would say one other thing about that is that, you know, I think when people go too far on this and then they don't trust anybody, or they only trust people in their Facebook circles, or they only trust people who are, you know, 10,000 miles away from the establishment, you know, they're putting themselves at risk as well. And so, it's kind of finding this middle ground where you're able to have conversations and you engage your medical team. You know, so if I'm working with a DBS, you know, it will defer to the neurosurgeon.

The neurosurgeon knows more about neurosurgery than I do. He certainly knows more about neurosurgery than most people living with Parkinson's do. Same thing, people who come to see me see me because I've gone to medical school, I know things, which does not mean I'm infallible. It does not mean I know everything about you, but it hopefully means that we can work together to find something that would work for you. But I think one of the keys there is dialogue, you know, and that between me and you, that we're able to come up with something that's right for you. And I learn from you, and you learn from me.

Melani Dizon:

Yeah. And I think that piece, the openness is, you know what you're talking about, it's, you know, if you find something and you hear something and that person that supposed expert is telling you something and is not willing to open that conversation, to have you ask other doctors or do something, that's just a red flag, it's just something to pay attention to. And it's not that you're never gonna believe anything. It's just that you're gonna have a more critical eye. And it's always, go to somebody like Benzi and he says, hey, well, that's not my area of expertise, I think you should talk to this person. That's a really good sign. You know, he's not trying to sell you something that he doesn't know. And that's a good clue when someone thinks they have the answer to everything. So.

Benzi Kluger:

Right.

Melani Dizon:

Okay. So, let's go...

Benzi Kluger:

Also, I was just look it up, Neil deGrasse Tyson, that is the person who said this quote. So, if you were, you're interested in getting this shirt, it's Neil deGrasse Tyson, and you can find this wonderful shirt.

Melani Dizon:

Awesome. We'll leave the link and I'm sure we'll find it and give it to you all. Okay. So, let's talk about some of these things specifically that people have been bringing up, let's first, do you feel



like you, is there anything left to talk about regarding stem cell? Because that's always a big question that we get.

Benzi Kluger:

The stem cell one, I think we covered the main points, you know, one is that currently there's no evidence for it. Second, it's dangerous. Third thing, which is again, concerning and sometimes surprising is there are, and this has been happening increasingly for a number of illnesses. So there is a resource which is a legitimate resource called [clinicaltrials.gov](http://clinicaltrials.gov) and [clinicaltrials.gov](http://clinicaltrials.gov) has all of the clinical trials in the world. And any time I do a trial, I have to register on it. There are people who are doing quote research with stem cells and it's posted on [clinicaltrials.gov](http://clinicaltrials.gov), but it's really not legitimate research. And so, they will enroll you in a stem cell trial, but they will ask you to pay to be part of their study.

Melani Dizon:

Okay. So that's a good clue.

Benzi Kluger:

That's a big red flag that you should never pay to be part of a research study.

Melani Dizon:

That's a big deal.

Benzi Kluger:

Yeah. And I think, you know, Mel, to your point before, you know, is this openness is really important and it's always important to get a second opinion and to talk to other people about it. And, you know, anytime people are discouraging you from doing that, you know, I would say, you know, run another direction because you know, either they don't have your best interest in mind and they don't want you to find something out or they're really just not very compassionate doctors who don't wanna listen to you or hear from you or are patriarchal. And so that can be a dangerous situation as well.

Melani Dizon:

Yeah, absolutely. Okay. So, let's talk about THC in cannabis. So, I wanna say it was probably three years ago, and we were both at that conference in Denver. There were probably 28 people at a round table of experts, MDSs neurologists, all of these different people, people from, you know, CBD companies and that kind of thing. And I just remember leaving there thinking, wow, there's 26 different opinions on whether CBD and THC is working. So, can you talk a little bit about that? You've definitely done some you know, research into that. What is the research?

Benzi Kluger:

Well, the, honest research that is out there is pretty minimal. So, this is another area where there are actually hundreds, literally hundreds of animal studies that have looked at various cannabinoids, which are various chemicals that are derived from the cannabis plant and in animals, you know, there is evidence that suggest that it might help with some symptoms of Parkinson's, there's evidence that it might be neuroprotective. But as I've said before, there are a lot of things that have proven helpful, including co enzyme, Q10 and vitamin E in animal models that when they've done large trials, it hasn't panned out. So, we can't take animal models as a way to make conclusive evidence to people, that people for the most part are not just large rats. And so, what works in a rat is not necessarily gonna work in a person. There have been some epidemiological studies and I've done some of these, and what that is just asking people, you know, do you use cannabis for Parkinson's?

And if so, what has been the benefit or harm? And these are going to be biased, because people who respond to the studies are likely people who have an interest in cannabis or who have used it, or had a good effect, and that people who aren't interested in cannabis or who haven't used it or had side effects may not fill out the survey. So, there's definitely some limitations there. To date, there have been several randomized control trials. And all of them, I would say are to be honest, are inconclusive, but they were really too small. They weren't rigorously designed, but none of them found a positive benefit for cannabis over placebo. So, at the current time, whether you're talking about a motor symptom or a nonmotor symptom there's not really a solid evidence base there.

That being said, you know, there is reason to believe, and there have studies in other areas, including for pain and sleep that cannabis may be helpful for certain symptoms. And so, if people are interested in trying it, and I have had patients and I've written licenses for people to use it, you know, that we follow kind of the same guidelines that we would use for medication. So, we start with a low dose, we use the same pharmacy, and we try to get things from reputable sources if we can, we always have a symptom that we're focusing on. And I, you know, certainly have had anecdotally, you know, and take this with a grain of salt that I've had people who've had improvements in sleep. I've had people who've had some improvements in anxiety, appetite, and nausea.

So, there definitely are some non-motor symptoms. There are also some people who feel like it's been helpful for their motor symptoms and smoothing ONs and OFFs, but there's no evidence behind it. So, it's anecdotal, and it's something that you would need to, you know, kind of do on your own and do some experimentation with. There are also, you know, on YouTube, you can find some very dramatic videos you know, which I would, again, you know, kind of put under the BS category. And these may be that they're very strong placebos for certain people, but there, you know, again there's no evidence. So, there's these dramatic

examples and there's websites that have, you know, very unbelievable claims, but currently the science is not there. And honestly, I don't know that will ever get there because if you stimulate those receptors directly, you actually lower levels of dopamine. So, so the idea that cannabis is ever gonna replace the other medications that we're using, you know, really doesn't make a lot of scientific sense.

Melani Dizon:

Right. And has there been any anecdotal that it's harmful?

Benzi Kluger:

Yeah. Yeah. And again, there haven't been great studies, but we know that there are side effects. And so, you know, it can worsen motivation. It can contribute to falls. It can lower blood pressure and people who are using a lot, it can cause nausea kind of ironically. And so there definitely are side effects from cannabis. And some of those can be very serious and they could lead to a fall or lead to cognitive impairment. And I guess that...

Melani Dizon:

And just the other downstream impact of nausea, or, you know, lack of motivation is gonna, you know, then you don't exercise, then you don't actually get the benefit. So, there's a lot of downstream impacts if it's not.

Benzi Kluger:

And I guess the other thing I would say about this, and this goes both ways you know, is that you do wanna let your doctors know if you're using cannabis or using supplements. And I've had friends, other physicians, who didn't know their patients were taking things and they were scratching their heads and wondering why this person was developing cognitive impairments and dementia. And it was only over time that that came out. And I feel like as a medical community, we do people a disservice by not listening with open ears and an open mind because if people don't feel safe to tell us things, then we end up missing opportunities, both to provide education, but also to provide, you know, safer guidance.

Melani Dizon:

Right, right. Okay. Let's talk about, let's go to the medical sort of more pharmacological and surgical devices. I have two questions or it's two statements about DBS. And I wanna address that. So, DBS will, or sorry for those people who are new, deep brain stimulation, DBS will cure Parkinson's or correct all symptoms. First of all, for just people that are sort of new to this community and don't know a ton, can you just give 'em a real quick thing about what deep brain stimulation is?

Benzi Kluger:

Yeah. So deep brain stimulation you know, I would say that there's, you know, kind of been two, you know, truly game changing things in the world of Parkinson's one is Sinemet or carbidopa levodopa which came out in the late 1960s and dramatically changed Parkinson's and you could watch the movie Awakenings and that's a true game changing medication and it doesn't come around every day. You know, everything we're doing right now is actually, you know, based for the most part on levodopa. And the second was deep brain stimulation. And the idea with deep brain stimulation is to put a stimulator in a part of the brain called the basal ganglia, which we know is affected by Parkinson's. And that, by doing that, and by providing electrical stimulation, we're able to affect that circuit to normalize some of the motor symptoms of Parkinson's.

Melani Dizon:

Great. Okay. So, DBS will cure my Parkinson's or eliminate my symptoms.

Benzi Kluger:

Yeah. And, so it won't, and it wasn't designed to do that. But I think sometimes people go into deep brain stimulation surgery with sometimes unrealistic expectations of what it can and can't do.

So deep brain stimulation can oftentimes help with tremor. It can usually help you with your other motor symptoms like slowness and stiffness, as much as your medications will, it may increase the ON time that you have, decrease OFF time. But it doesn't tend to do more other than, you know, reducing dyskinesia and tremor than your medications would. So, if anything, it can sometimes worsen thinking and memory. If your gait and balance are not better with medications, DBS is unlikely to make those things better. I published a study with Michael Okun and a group at Florida a while ago, and one of the take home messages from that paper was that when people get disappointing results from deep brain stimulation surgery, the number one reason is that they got the surgery for wrong reason. They got the surgery thinking it would help things that DBS is not meant to help.

Melani Dizon:

Yeah. And then the other side of that, the medical bullshit side is that, are people performing DBS surgery on people that shouldn't get it for bad reasons, right? And how do you like point that out? I mean, it seems crazy that somebody would give somebody brain surgery that it's not gonna work for, but if they had unrealistic expectations, they were maybe getting it from somewhere.

Benzi Kluger:

Yeah. And it's not you know, it's really not the fault of the patients. You know, in an ideal setting, if you're getting deep brain stimulation, you're going to see a team of people who will do an assessment. And part of that assessment is checking your thinking memory. Part of that assessment ideally, would be seeing a psychiatrist as it can sometimes affect mood. Part of that would be seeing a movement disorders neurologist who has expertise in Parkinson's. And also, you want a neurosurgeon who has expertise in that area. So, you really want to have a team-based approach. Some of those people actually in that series didn't even have Parkinson's disease, you know, and that would be something that would ideally would come up if you had a movement disorder neurologist on the team. But if you're seeing, you know, somebody who's you know, just a neurosurgeon by themselves or seeing, you know, somebody in private practice who doesn't have a lot of experience, who's maybe working with a medical device representative and that's the team, you know, that can be a dangerous situation.

It's not always dangerous, but it can be. You really do wanna work with an experienced team or get a second opinion. But yeah, it can be an area where I've seen people who've gotten hurt from DBS and who've had bad outcomes from DBS.

Melani Dizon:

Okay. So, another piece on DBS, you should really delay DBS because it's gonna wear off.

Benzi Kluger:

Yeah. And, I would say that, you know, the flip side of that, you know, there are some people who are, both patients and doctors, who are very eager to do DBS and to do DBS as early as possible. Not everyone's gonna need DBS and DBS doesn't solve all problems, so that's not the right approach. But the flip side of it is that delaying DBS for too long may get you out of the window for DBS. And there in particular is that as Parkinson's progresses oftentimes people will develop problems with thinking and memory and those problems with thinking and memory increase the risk of deep brain stimulation surgery. And so, there is a window where DBS is gonna be safe and effective. And if you wait too long, you could miss that window. And the same thing is true it's kind of reading your mind and predicting questions since we talked in advance is with levodopa or Sinemet, is that for a long time, there was a thought that you should delay medications for as long as possible because the effects are gonna wear off.

And what actually is happening is that as Parkinson's progresses, the medications are less effective and Davis Phinney Foundation has been great about this, but I think the philosophy is, is that you want to be as independent and as active as possible. And part of that is, is that if medications help you to be more independent and more active, then they're your friends. And so, you don't want to delay medications. You don't wanna tough it out. You don't want to be kind of constrained because you can't move very well and then expect taking medications later

are gonna be better. In fact, there are studies showing that that strategy really is not a great strategy for people with Parkinson's.

Melani Dizon:

Yeah. And you know, if your Parkinson's is getting in the way of your quality of life, why delay that, right? Like live a great life while you can. Oh, another really big one that we get a lot, there's an ideal diet for Parkinson's.

Benzi Kluger:

Right. Yeah. And I mentioned this book, Grain Brain, which was a New York times bestseller, there's, in the skeptics community, there's a lot of things that have torn this book apart, you know, and I would say that there's really not good science behind it. And this would be, you know, actually if we go down our list of you know, the bullshit detector, there's a lot of things there, you know, one is that the expert, you know, does not have a background in nutrition. So that should make you, the second is that there is a lot of unbelievable claims in that book, mainly that avoiding grains while you know, cure Parkinson's and other things like that, which is not well supported. And there have been other diets there's ketogenic diet there's a whole host of you know, gluten-free diets that have been claimed to help with Parkinson's and to date there are no studies that support any diet for Parkinson's.

You know, what is important is that you have fiber in your diet to help with constipation. It's important that you stay well hydrated as people can have low blood pressure and faint. It's important to watch your weight. And in fact, in Parkinson's, particularly advanced Parkinson's, weight loss can be a big issue. And so, you wanna make sure that you're not losing weight and then in general, you wanna eat a heart healthy diet and things that are good for your heart and good for your blood vessels are gonna be good for your brain. But beyond that, there's really not, you know, nothing specific and there's nothing out there that's been proven to reverse Parkinson's or be a cure. I guess the last thing too with diet is, and this is one of the dangers of Grain Brain, is that if you were to follow that book you may be eating a lot of protein and that can interfere with the absorption of medications like levodopa. So could actually make things worse and it could make constipation worse. You know, from following some of these diets to the T.

Melani Dizon:

Yeah. And somebody just said about yogurt interfering with absorption of carbidopa levodopa, it sort of depends on the type of yogurt. You can have a really high protein, yogurt that could, so you definitely have to pay attention to that. So, somebody asked about thymine B1, but we're we kind of covered the whole...

Benzi Kluger:

Yeah. Thymine is one where there's not really evidence for, in Parkinson's. And I would say, you know, vitamin B6, which is in a lot of supplements is actually a vitamin that you can overdose on. So that would be another one where there's potentially dangerous and ironically vitamin B6, which if it's too low can cause neuropathy, if it's too high, can also cause neuropathy. And I've seen people in clinic who've had nerve damage because of taking too much vitamin B6.

Melani Dizon:

So, somebody said, someone told me if I meditated hard enough, I could cure my Parkinson's. You know, that is just like, well, gosh, no one would have it. It reminds me of, I feel like this was the 1970s. And I bet all of you will remember this that were watching TV at that time, when Cher came on, she had a little bottle and she was like, you know, she was like in a leotard, if a perfect body came in a bottle, everyone would have one. You know, it's like that thing, there would be no Parkinson's. If there was a cure, trust me, we would be promoting it, everybody would have it. Right. And the other thing that we haven't really talked about that I think is super important, especially when I thought about it around DBS is that this is also where having a community of people with Parkinson's in your world, whether support groups, care partners, friends, people in your exercise class is really great because they can talk to you like I had DBS or, wow, they'll ask you questions that maybe they have a really great doctor.

You don't have such a great doctor, or you don't have a doctor that's really digging in, and they will give you, oh, you should think about this. You should ask this. It's one of the huge benefits. And also, for people to do some gut checks and to say, hey, I heard about this. What do you think? And, you know, they can talk about what their experience was. We only have a few more minutes, but I really wanna talk about exercise really quickly. So, let's just say, only if I exercise at super high intensity, will I receive any benefits.

Benzi Kluger:

Yeah. So, the data on exercise and this is also true for Alzheimer's disease and is really impressive. You know, so I would say there have been studies now of Tai Chi, of using exercise bikes, of treadmill, and they've all shown potential to slow down the progression of Parkinson's. So, that really is true. Strength training as well. There is a study of progressive strength training. What we don't know is what is the optimal dose? And I would say that the evidence, you know, suggests that there is a, you know, some dose effect in that even at low levels and in the study I was a part of at the University of Colorado with treadmills, there was benefits, you know, from exercising at fairly low levels three to four times per week, that it seems like more rigorous exercise is better.

And it's a balance. I definitely have also seen people who have injured themselves, who have made their fatigue worse because of exercise. There's been some interesting discussions in the

world of geriatrics of kind of distinguishing between exercise and activity. And have found that sometimes people do themselves a disservice because they exercise really hard for a half hour, and then they're on a couch the rest of the day because they can't move. And so, we're also wanting to think about kind of global activity levels. And so, it is finding an area that's comfortable for you initially and then I think that the data would also support that you do wanna try to push yourself and that's, you know, not pushing yourself to the point of injury or discomfort, but that you're progressing in some way.

Melani Dizon:

Right. And we actually, I just did an interview with Mike Studer and you guys can find on our website, we just did a whole talk about neuroplasticity and exercise and Parkinson's. I think there are a lot of really interesting nuggets there, but you know, one of the things you alluded to it here is the, you know, if you work out really hard and you're on the couch for the rest of the day, that's no good. The last thing you wanna do is exercise your way out of activities of daily living. Those are the things that you wanna do. And just like you wanna push yourself a little bit in exercise. You also wanna push yourself a little bit in those activities of daily living. Like there's this idea of learned non-use right. And if you are always having your care partner, do something for you and you're not doing it, then you learn to not do it, and then you lose that skill. And so, exercise is a part of sort of that everyday living. And the last thing you wanna do is hurt yourself, doing exercise. Then you don't get the benefits of exercise and you also are less, you'll be less independent.

Benzi Kluger:

Yeah. And really related to that. And I know this is a concern for a lot of people is memory. And there have been a number of things around, you know, certain computer games or, you know, crossword puzzles or Sudoku. And it's similar to exercise that there's not really any particular brain game that's gonna be the best, but it is about staying as active as possible, you know, and whether that's Scrabble, that's staying socially active, listening to music, learning a new language. You know, I think for all of these things, if you can find something that's fun and you enjoy, and you can make a good habit of, that's probably gonna be the best thing for you.

Melani Dizon:

Right. And novelty makes time like go longer. It feels like, you know, when you learn something new, not only is it helping your brain, but it also you know, makes time slow down, which everybody wants a little bit of that. So, oh my gosh, like, I think we could talk about this forever. I really appreciate you being here and going through all of this with everybody. I am going to make sure that you all have a copy of the list that Benzi talked about today, and I'm gonna make sure that we send whatever links, we'll definitely send the link to the t-shirt. We might all have one here at the office, because they're pretty amazing. We will get the recording, you'll get the audio, the video, the transcript, all of that. And Benzi, I can't wait to have you back for another topic, whether it's palliative care or more on this



Benzi Kluger:

Sounds great. Well, thanks so much for having me. I always appreciate the opportunity to talk about this. It is a passion of mine, and you know, I think going back to one of your first questions is you know, I kind of saw that this was an opportunity that I could really help people and, you know, honestly save lives. And unfortunately, there hasn't been as many voices I think, there's a lot of bestselling books pushing bullshit. There haven't been that many bestselling books helping people avoid it.

Melani Dizon:

Yeah. Well, we're gonna make sure that your voice is heard loud and clear as far and wide as we can.

Benzi Kluger:

Sounds great. Thank you.

Melani Dizon:

Thanks. Thanks everybody.

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