Introduction and guest background

Welcome to another really wonderful interview at the, miss another Immune Summit. I'm here with my good friend, Doctor Brandon Bieber. And let me, do his bio.

Now, doctor Bieber is a board certified neurologist who has subspecialty training in multiple sclerosis and other neuro immune conditions. And I'm going to have him explain that specialty training, because I know many of you are able to go to Ms..

Center and Ms.. Specialist, but some of you, particularly those of us living in more rural states such as Iowa, we, are getting the most care from a general neurologist.

He has a, YouTube channel. He post videos about Ms.. Every Wednesday. And I'm very excited that he's interviewed me a couple times on his channel. He has a book, resilience in the face in the Face of Multiple Sclerosis, which is on Amazon.

And it's about five people who've had Ms.. Who still lead really wonderful, incredible lives. So all of you who are listening, thinking that life has come to a screeching halt because you've been diagnosed with Ms..

I'm here to tell you that's not the case. And Brandon will tell you, also, that's not the case. And he has, many publications on, Ms.. Epidemiology. He also has a Twitter.

Brandon underscore Bieber. And with that, welcome, Brandon. Good to see you again. Now, the first thing what I'd like to do is have a little conversation about the difference between a general neurologist and a, neurologist who specialized in Ms..

In her immune care. How does one get specialized? What's that process look like? Well, basically, when I was doing my training in residency to become a neurologist, I became interested in multiple sclerosis.

I had a mentor who inspired me. And, you know, I started pursuing fellowship positions. And so after I finished my neurology residency and a lot of that is inpatient training, we have mostly experience with, you know, patients with brain hemorrhages and strokes and things that require inpatient care.

And we have a little less experience with so-called outpatient diseases like Parkinson's disease and multiple sclerosis. But I knew I wanted to specialize in this and that I needed more training.

And so I ended up doing a fellowship position. And usually people do 1 to 3 years after residency. I did mine at USC and Kaiser Permanente. I actually did one and a half years, which is unusual.

And that's because my organization was basically desperate for someone, and so they wanted to hire me as soon as possible. I plan to do two years. People who are more clinical neuro immunologists may just do one year.

People who are more academic, like they want to get a master's in clinical research. And I watch a lot of papers. I'm not one of those people. They may do three years just because they need more formal research training.

They need to learn things like doing, you know, advanced statistics in order to publish their results. Yes, we have some of those folks here at Iowa, and they do, basically get a master's in clinical research, design and statistics along the way.

So in the fellowship, trained, Ms.. Specialist, do you have a sense of how many there are in the country? I don't know that, this is a smaller specialty.

You know, obviously things like stroke and epilepsy, these are very common diseases, multiple process isn't rare, you know, rough risk, 1 in 500 in the United States, but it's a little bit less common than those diseases.

Training as an MS specialist

For instance, where I trained, I was the only adult neurologist doing the training program. There was actually another PDR pediatric neurologist. So a lot of these fellowship positions is just 1 or 2 people and even a lot of big programs like UCLA.

Some years they may not take on any fellows, you know. So I don't know the exact number, but it's definitely a smaller fellowship. It's not even a Sigma accredited.

You know, I just have a little certificate. I'm not board certified in multiple sclerosis. I'm just Board of Certified neurology because there is no board.

So it's a little more informal. You know, back in the day, you know, almost everyone with Ms. was treated by a general neurologist. But you know, with some of these medications they're more complicated.

They could cause more side effects. You know, it becomes a little bit more difficult for a general neurologist. But, you know, there's some excellent general neurologists who have an interest in it who are dedicated to it.

Keeping up with the research, who could be very good. So I'm not saying they're unqualified, but it's kind of getting harder and harder for a general neurologist to do it. Well.

And I know many of you who are, listening to these interviews are in a more rural area, and so you may not be able to get into an Ms.. Center, in a urban center, it becomes easier.

And here, in Iowa, we have, the Ms.. Center here at the University Hospitals, and there's another one in Des Moines. So in rural America, even getting a neurologist can be, very challenging.

So I know, granted, I've had some conversations about, the measures that is very common in Ms. research, and that's the expanded disability status scale, which is, a measure of disability.

And so, granted, could you tell our audience a little bit about the EDI ss, what it is and why it's used in research? So this is a little bit of a, you know, esoteric subject to a lot of people, which I understand.

But it is important because, you know, if you're looking at an article, you want to know how that applies to you. And just to take a big picture view of it, you know, what is a good outcome in any research study?

And I would say very simplistically, it's an outcome that matters to you, the person with the disease. You know, just to give an analogy, let's say you were going to change your diet or take a medication for cholesterol to lower your cholesterol levels, let's say, to lower your low density lipoprotein or bad cholesterol.

You don't really want to lower your cholesterol. You want to improve your health. You want to prevent heart disease. You want to prevent strokes. That kind of thing.

So that's sort of a good outcome, something that really means something to the person with the disease. So the SS is a measure of disability and it's a 0 to 10 scale, zero being zero disability, no problems related to mass and ten being death due to multiple sclerosis, with higher numbers being worse.

And it's been used in Ms. research for a long time. And it's a very complicated scale. It's difficult to do and it's I can't explain the entire scoring system.

I have a YouTube video on it if you want to take a look. But basically, you know, 0 to 3 would be mild or disability four would be sort of moderate disability, usually associated with some difficulty walking long distances.

At SS six, a cane is needed to walk 100m, so you might be able to walk short distances without any assistance. But for longer distances you would need to use a cane for balance, and it's 6.5.

You would need a walker to walk and it's higher levels than that. There are increasing levels of disability now this definitely matters. You know, having a higher ed dose is worse than having a lower Ed.

Yes for sure. So based on the definition I gave, it is a good and meaningful outcome measure. But it has a lot of problems. One thing is that if two people evaluate someone with Ms., they could come up with different numbers, maybe a difference of 1.5.

Also, it's a very non-linear scale, like someone with an EDS of three might be functioning much, much better than someone else with an index of two. Let's say, for instance, you, walk with a cane because your balance is pretty good, pretty bad.

But you can walk long distances and get around. And let's say you have very good cognitive function and let's say so your EDS is 6.0. And let's say over the next 1015 years you significantly worsen.

And now you can only walk shorter distances with a cane and you get very fatigued. And now you develop significant cognitive impairment. Your EDS is still 6.0.

So it's not really sensitive to picking up differences, particularly in people with more existing disability. So how exactly are you going to research whether a diet or lifestyle change or medication is effective if you can't see the difference and it's just the same score?

There are a lot of other problems.

EDSS disability scale and its limits

It's really biased in favor of lower extremity function like strength and mobility of the legs. It's not as focused on use and dexterity of the hands or cognitive function, or pain or fatigue.

It just doesn't really pick those things up. So in my opinion, it's actually not a good measure of disability. And people with M. S.. So let's talk about another measure that I like a lot.

And we use in our studies the Ms. functional Composite. Can you tell our listeners what that is. Yeah. So I think this is a better outcome. It's a composite outcome.

And there are a couple of different versions of it, but basically it adds together four different measures of function. One is the time 25ft walk scale, which is how fast you can walk 25ft.

So a person without any disability could probably do it in about four seconds. And it's a continuous scale. So even if you're a little bit slower maybe it would be six seconds.

So that's something we can measure. The other test is a measure of hand function called the nine hole peg test, where there's a little board with holes in it, and you take little pegs and put them quickly into the holes and then take them out.

And so that requires a lot of different things strength and dexterity of the hands and also vision. And there's another test called low contrast visual acuity, which is kind of an eye chart.

But the letters are dimmer so they're harder to see. And it's very sensitive to picking up differences in visual function. And the last thing is a test of cognitive function.

And there's a test called the symbol digit modality test where there are a little symbols and they correspond to numbers. And you have to sort of break the code and fill in the numbers as quickly as possible.

And there's another version of the Ms. functional composite where they use a different cognitive test called the pay set. But all these measures, something that people care about, you care about your cognitive function, your walking speed, your vision, your hand dexterity, and you care about all of them independently.

So adding them all together to create a total score makes sense. So I think that's a better outcome. Okay, so are there I know we're using that in our trials now.

Are there others researchers that are using the combination of these four tests there are however, there is a problem where let's say it's a pharmaceutical company.

They mean have to use the edcs, you know, the regulators like the FDA, you know, they're kind of used to the AEDs and they're comfortable with it. And, you know, there is some value that people know what the number means, their experience with it.

But the problem is it's just not a great outcome. And I think it leads to people, especially people who are older with progressive Ms., who may have some existing weakness of the legs, like they're walking isn't great.

It ends up getting them excluded from clinical trials. And I actually had a petition and we were just talking about this before you turn the camera on, I actually sent a petition to the FDA to ask them to consider these composite outcomes.

So I'm a big supporter of this. Yeah. I mean, I think it's super important that we find, a way to include more of these measures in our, research. I know, I know I care a lot about fatigue.

And that measure is rarely considered in, drug studies. They, they, and let's talk about the measures that are used to get approval for adding a new drug for, use in the Ms..

What? What do the FDA regulators look for? To decide that a drug is suitable? So a clinical trial could have a lot of outcomes. It could have ten different outcomes.

MRI scans and neuro filament light chain, which is a protein that is sensitive to breakdown of the central nervous system. But there's always going to be a primary outcome, something that's specified in advance to see what the study is looking for.

And that will determine whether or not it was a positive trial. And typically in people with multiple sclerosis, if it's a relapsing remitting multiple sclerosis trial, the primary outcome is going to be relapses.

Now, relapses are a good outcome. I mean, no one wants to have a relapse. No one wants to have, say, blindness in one eye and have to maybe go to the hospital and get steroids to get better.

And so it's definitely clinically meaningful. However, people are increasingly questioning whether this is a good measure of long term success of treatment of multiple sclerosis.

So if you look at people with Ms. in the first few diagnosed years of diagnosis, there is a correlation between number of relapses and long term prognosis.

So some people seem to have more aggressive mass. They have a lot of bad relapses early on. That definitely is correlated with long term prognosis. And maybe if we can stop some of those relapses, people will do better.

However, study is looking at the big picture of Ms.. So looking over a 20 year period, the number of relapses doesn't really correlate with long term disability.

And it seems that the timing and the pace of progressive Ms. is much more important. And the reason is a lot of people with relapses do recover from them.

And so they're not necessarily that correlated with long term outcomes. Also, in people with progressive multiple sclerosis, having relapses does not seem to be associated with worse progression of disability.

So some people have progressive Ms. plus relapses, some people have progressive Ms. without relapses, and they seem to be equally bad. So probably instead of looking at prevention of relapses, the better outcome would be prevention of disability as measured by something like the Ms.

Functional Composite. Well, let's talk about. So we've zeroed in progression of disability is the most important, measure. We aren't necessarily measuring that.

Now, everyone who's what watch all these interviews is now going to say like, okay, so what what could I be doing to reduce the progression of my disability in your clinical judgment, Brandon, what are you telling your patients were the things that they can be doing to reduce the risk of progression?

Well, I there is evidence that disease modifying therapies reduce the risk of progression. The effect is greater in people with relapsing Ms. versus people in progressive MSR treatments seem to be better for people with, you know, relapsing Ms.

is just the reality. You know obviously these medications do cause side effects. You have to weigh the benefits versus the risks of that. You know, in addition to medication.

I think lifestyle is very important. Obviously, you'd be a huge proponent of this. There is very good evidence that exercise reduces disability progression in Ms.

MS Functional Composite and trial outcomes

and there's very good evidence that overall health is correlated with prognosis to some extent, you know, so the risk factors for progression of Ms. do correlate a little bit with like the risk factors for heart disease say like diabetes, high cholesterol, sedentary lifestyle.

You know, so I think having a good diet and a regular exercise program is very important. Do you have, opinions about what kind of exercise you're wanting your patients to do?

Well, my personal bias is any exercise that someone enjoys and is going to sustain on a regular basis is likely to be the most beneficial. You know, if you hate running, it's probably not going to work out for you.

You know, for people with more disability. Some people find that cycling on a stationary bike or, or swimming is something they're able to do more of.

Like people may not be able to walk long distances, so that may not work as well for them, but they can go a little bit harder or say on a stationary bike, in an air conditioning gym, or swimming when it's when it's cold.

So for people with more disabilities, I think those things work well. And, you know, some people, grief resistance training works well for them. Like they really can't do an hour of intense exercises, but they can do 15 minutes of resistance training and take a break.

But honestly, my personal opinion is, whatever you enjoy and want to do is something you're going to sustain. Like for instance, I like jogging and running.

I enjoy that it's natural for me, and that's the type of exercise I'm actually going to do. I don't particularly like swimming, so I'm not going to do that.

It's not going to work for me. You know, I liked running a whole lot. And then when I couldn't run anymore, I started swimming. And so, yeah, I swam for years.

And then I got, so, that swimming got difficult. I did water aerobics, you know, and and, you know, fortunately for me, I can go back to running. Although, though I like bright outside, I don't have the judgment to stop in time.

And I and I've stumbled a few times, like, okay, I guess I'm going to just run on my treadmill. So that, you know, I'm old enough now that I really don't want to stumble and risk, you know, accidentally breaking my wrist.

So, you know, exercise for exercise in a way that keeps you safe. So be sure that's fun. Diet. Well, what are you telling people about healthy eating?

Well, this is an ongoing topic. You know, I know everyone has their own opinion on what the best thing is. I want to keep some semblance of being unbiased because I'm actually involved in some research.

We're looking at people who are over age 55 with multiple sclerosis. And of course, there's a high variation in disability in older people with MSM. People are doing great. They're doing really well.

Some people, they have significant disability. And the question is, is it luck or is there some correlation with lifestyle, you know, vitamin supplements, what you eat, sunlight exposure, smoking.

So we're looking on that. I don't want to be too biased because I sort of want to accept what the data show us. You know, I think that many people would agree that, you know, eating processed sugar and processed starch is bad for your overall health.

That can't be good. There's some epidemiologic evidence that, for instance, consuming more dairy is linked to higher rates of M. S.. I don't think it's definitively proven that dairy is bad for Ms..

But, you know, dairy is not necessarily nutritionally. I think it's reasonable to avoid it. If you can maintain that diet. There may be an association with salt intake, too.

Miss higher sodium diets, salt is abundant in processed foods. Natural foods have some sodium, but much less, of course. More controversially, there may be a link between saturated fat and multiple sclerosis.

You know, this was promoted by Doctor Roy Swank, and I understand you may be skeptical of that. Of course, epidemiologic evidence is very weak. You know, there are different things happening in different countries.

It's not necessarily just due to one factor. You know, someone actually pointed out to me in a comment today on my YouTube channel that, hey, the Eskimos and the Maasai eat a lot of needs.

They don't have high rates of M. S. Which is true, although they're different from Americans in other ways. I wouldn't think that there's a single proven diet for multiple sclerosis.

Yeah, I completely agree. So everyone is listening. There are many diets that humans have had great success with as we migrated out of Africa. We eat many different foods and many different ecosystems, but there seems to be one diet that is really bad for health.

A lot of added sugar, a lot of white flour, lots of processed foods. And when you let other people cook for you in the fast food industry, with all the food additives and food like chemicals added to the food uniformly, you know, every say, I've looked at that, assuming those kinds of foods lead to worse health outcomes.

So I doubt that there's going to be one diet that is better. Whether it's the paleo, the low fat, the, ketogenic, intermittent fasting, low glycemic index, I think all of those diets would probably be way better than the standard American diet.

So I think it's going to be super interesting what you find, Brandon. And, the various researchers that I know that are investigating a steady diet when we do our diet studies, we have to define what we're asking people to eat.

So there's a diet that we investigate, in a intervention study that is different than the observational study. And nearly every interventional diet study has shown that the interventional diet does better than the usual diet, which is eating more of these processed foods.

Lifestyle factors: exercise, diet, smoking, alcohol, and sleep

So I think Brad and I are agreeing, eat more of these radical things known as high quality protein sources, these radical things known as vegetables and fruits, and less of the stuff that you get from the center of the grocery store that's been manufactured by someone else.

You can't go wrong with that for sure. That will improve your health in all sorts of domains. Let's talk about tobacco and vaping. So there is an association between smoking and EMS.

The association is not strong. People who smoke have a slightly increased risk of M. S. also people with Ms. if they smoke they have a slightly worse prognosis on average.

So it's not a huge effect. It's a small effect size. But of course if you're smoking, you should quit smoking. And interestingly, the most successful method, the method most commonly used to successfully quit smoking is actually to just quit.

Just take all your cigarets and lighters, throw them in the trash, and just stop smoking. Believe it or not, that is the most common method used to successfully quit.

Sometimes it's helpful to pick a quit date and tell your friends and family to help you out in case you're tempted. So I definitely recommend that with vaping.

You know, I presume it's bad, but I haven't seen, you know, definitive evidence on that. You know, marijuana, alcohol do not seem to be specifically associated with Ms..

They have their own risks, but they're not they don't seem to to cause or worsen miss, based on observational studies. That's sort of interesting. I know some observational stuff that we looked at.

I was quite surprised that low dose alcohol and, you know, occasional use, in our little observational studies, I was quite surprised. It seemed to be protective.

Binge alcohol was definitely not, you know, excessive alcohol. So high use. Definitely not. But, you know, occasional use was was actually, slightly protective.

And I was quite surprised by that. And I think that's true for heart disease also, you know, but I see a lot of people who have major, major problems with alcohol.

You know, alcoholism, alcoholic liver disease. You know, when I talk to the addiction people in our hospital and asked them, what's the worst drug causing the most problems?

It's not math. Math is really bad here in Los Angeles is actually alcohol. So, you know, if you have a problem, you definitely have to look into that.

But if you're not an alcoholic, you can control it. You're using a modest amount. It seems to be safe. A lot of people with Ms. actually don't drink alcohol just because anecdotally they are more sensitive to it, like they feel more drunk with it than before they got sick.

So I find a lot of my patients don't drink anyway, but it doesn't specifically worsen. Ms.. Well, you know, I personally find that, I can have a small amount of alcohol.

I enjoy that, but if I have what other people would consider to be, you know, a very moderate amount, my balance,

is impaired far, far more significantly.

And so people think I'm severely intoxicated, like, well, that's you know, I just don't want to deal with that. So I have a tiny amount of alcohol, if I choose to drink.

Yeah, I've heard that story before for sure. Yeah. And I expect that is that is true, you know, and, you know, when my neurologist encouraged me to start using walking sticks and I was resisting that, he said, you know, do you want people to think that you're drunk midday, or do you wanna use a walking stick?

And I'm like, yeah, okay, you got a point. So I started using my walking sticks. But also meant that, because I realized that my balance was so easily disrupted by even small amounts of alcohol that I really reduced my alcohol intake, because I didn't want people to think that I was, seriously intoxicated.

So if all of you who are listening, that may be why, you have moderated your alcohol. To some degree. Sleep. Do you talk to your people about sleep? I do sometimes, you know, obviously a lot of people have difficulty sleeping.

One of my colleagues at Cedars-Sinai who's, you know, an older physician who's been doing this a long time, told me that she believes a lot of her patients who are very old, have had Ms.

for a long time with minimal disability. She feels a lot of them report good sleep. So there may be something to that. I can't say I personally noticed that, you know, in terms of the role of a neurologist, you know, I try to like avoid medications that are going to disrupt people's sleep, like stimulants taken too late in the day, you know, and if people have, you know, symptoms that keep them awake like muscle spasms, you know, I try to help them with that.

You know, there's some anecdotal evidence that it may be it may be important to get good sleep. I certainly think that's true. Okay. Do you use melatonin?

Do you encourage melatonin for the people who have difficulty with sleep? Yeah. I'm not a proponent of, like, pharmaceutical sleep aids, you know, like Klonopin and Ambien and things like that.

I think it's generally a bad idea to go down that route. But, you know, melatonin, 3 to 6mg half an hour before sleep. Valerian root. I think that's very safe.

The effect is going to be modest. You know, it's not going to be life changing. But I think that that is totally safe. And you know, it has a modest effect, but it works for some people.

The other thing that I talked to people about is light, you know, get out in sunlight in the morning. And, I've redesigned the light in my home, so I have the ability to switch to red light, in my living room, in my bedroom.

In my bathroom. So in the evening, I make sure I don't have any full light spectrum. On. I have a warmer light. And I switched to red light, in the evening as well.

Yeah. Like, if you ever go camping and it's you're you're outdoors all day, and it's bright all day, and then it gets dark really early. You'll find that you sleep very well.

It's hard to recreate that in our modern society. But you're trying. It sounds like I myself am like a really bad insomniac. I'm a bad sleeper. So I struggle with this all the time, but I definitely try to keep the lights low later in the evening.

I don't have your your light system, which sounds like a good idea. Well, I have had insomnia all of my life and so, I've been steadily working on improving my light.

That certainly has helped me out a lot. Now, one last thing I want to talk about are early life, stress, adverse childhood experiences. And I'm wondering, do you have this conversation with any of your patients?

As you're, in the initial intake or as you're following them over time? Well, so there are a lot of studies looking at the risk of developing multiple sclerosis.

Some of them have reported it that things like early head traumas or early life traumatic experiences, you know, may correlate with risk of M. S. it's not a consistent finding.

You know, some studies don't find that. I have many patients report to me that their onset of Ms. or their symptoms of Ms. have been worse during a period of severe stress, whatever that might be.

You know, I so I certainly do talk to people about that. I think that, you know, whether or not that kind of thing causes that. Ms. is uncertain. I definitely think chronic stress can worsen the symptoms.

And, you know, a lot of people do benefit from therapy or even medication or medications if that's a factor. Yeah. You know, I got, tuned into this in one of our trials, when I was doing the intake, for this particular trial, I was I was struck that all but one of my patients reported, really serious, early childhood, adverse childhood experiences.

And so that got me wondering, and, it also got me reflecting on my own life. Brandon, when I was eight, my sister died, which was very traumatic for my family.

And I created enormous, family, struggles for us. And so I've started talking to my patients as I, bring them into my practice about, the early life stress.

And I asked them if they've gone to see any mental health professionals to work through, any of those wounds that they might still be, experiencing, to help resolve that.

If you find someone who has, you know, the severe psychological stress either currently or earlier in their life, how do you handle that in your practice?

Brandon? Well, that's not necessarily my area of expertise, you know? So I talk to people about it, you know, and I encourage them to try to think about it a little bit and not just bury it away.

And I usually refer people to a therapist if that's an ongoing issue for them. Yeah. So all of you who are listening, if this makes you sort of wonder, what's serious psychological stress now or early in your life?

A factor for you, you know, talk to your primary care practitioner. They can help get you referred to a mental health professional. Talk therapist, talk to your neurologist, your specialists.

They can help you get referred to, a specialist. So I'm sort of looking at the, live.

Stress, trauma, and mental health support

So we've covered diet, we've talked about exercise, we've talked about tobacco vaping, sleep aces. I guess we haven't talked about stress management yet.

Do you have? How do you approach that with your patients? Yeah, I, I do think that many people report that their symptoms are worse during periods of stress.

I think different people, different things work for different people. You know, for me, I would say exercise is a big stress reliever for me. You know, for a lot of people, meditation works.

You know, for a period I was into this form of mindful meditation and, you know, there's some good books on it if you don't know how to do it. And some like, simple guided meditations if you go to the website or abracadabra, she has some really nice recorded guided meditations that could help you.

And, you know, my sister is actually a therapist, and she does this with her clients that she helps guide them

through meditation and kind of teach them how to resolve stress along with cognitive, behavioral therapy.

And I think different things work for different people. But if you experiment, you can probably find something that works for you. Cognitive behavioral therapy.

Could you explain what that is? Well, sometimes people have patterns of behavior and patterns of thinking. Like, for instance, let's say someone is having worsening symptoms of Ms..

Like they have worse numbness or weakness. They may tend to think very negatively and be very worried and sort of compare their stress, you know, but with training, you know, sometimes people are able to change their thinking patterns and train themselves to think more optimally, think more optimistically, I should say think instead of being worried that I'm going to become progressively more disabled, I'm going to think, well, what do I need to do to I need to change my diet, make sure I'm getting better sleep, go see my neurologist, see if I'm potentially having a relapse and need steroids, and try to think more practically and optimistically.

You know, and again, I'm not a therapist or psychologist, but I think that's something a professional can really help with that. Yeah, I think that is I've looked at a number of studies of cognitive behavioral therapy.

And very helpful for fatigue, very helpful for, cognitive cognitive issues. I was quite surprised about that and helpful for, pain management as well.

And then there's another variation where it's helpful for, insomnia. And, you know, actually, there was an online program for that, and I'm using that myself right now to help improve my sleeping, and I did, I was very impressed.

It's been very, very helpful. So, Brandon, I always really, really enjoy our conversation so much. Now, I sort of think back, because we've covered a lot of stuff in terms of measures, for disabilities, lifestyle factors.

What is the one thing you'd really like our listeners to take from our conversation today? Well, you mentioned it earlier, measurements of fatigue. And then you kind of hinted at the idea of patient reported outcomes.

And so people think about like fatigue scales or overall quality of life scales as being unscientific or, you know, not objective. But in reality, those are very good outcomes of clinical trials.

Because remember when I said at the very beginning, a good outcome is something that matters to you. And many people with Ms. think of fatigue or cognitive fog as being their worst symptom, more disabling than their vision problems or their mobility challenges.

So those are actually good outcomes. Now, you know, they're not perfectly objective, of course. And that's why it's important to do randomized trials.

And it would be nice to see some objective evidence in addition to improving fatigue. But I actually think that that's a great outcome. You know? Ms.. Related.

Quality of life surveys fatigue status scale. These are common surveys used in some multiple sclerosis trials. I think they're a good adjunct to more objective measures of disability like the Ms. functional composite.

And I think they should be done more in these big phase three trials. And I'm glad to see that you're doing them and your clinical trials, and they're not that expensive or time consuming to do, and they are very meaningful to people, you know.

And, I thank you for bringing that up again. Everyone who's listening, I want you to know, and I'm going to ask Brandon to comment on this, what I, what I think is the most sensitive measure of, improvement that people respond the quickest.

Is there. Energy is improving. They're less fatigued. And I can see that when people are successful at implementing

a better diet and exercise program, a, stress reduction program that in three months, 50 to 75% are coming back saying, you know what, doc?

I am feeling better. My I can tell my energy is better. And branded as that match your experience as well? Yeah, that does match my experience. And also, you know, when I'm seeing a patient, I may examine them.

And I have two patients and their exam is very similar.

Patient-reported outcomes and closing resources

They have the same degree of objective neurological deficits. But one says, you know, I feel great. I can do everything that I want to do. And the other says, I feel terrible.

You know, my M. S. is really bad. And often that difference is fatigue, energy, cognitive sharpness. Those subjective things are very important. Are vitally important.

And finding, a medical symptoms questionnaire, that's, that's a questionnaire that Mark Hyman really likes. Yes. On his website, you could, complete that score yourself and look at the domain that is most troublesome for you, which might just be 5 or 6 questions that you could then track, every three months to see, like, okay, you know, my numbers are getting better.

In fact, my energy is improving and my lifestyle program is doing really well. And then that gives you a lot of reassurance that things are going well for you.

Absolutely. Okay. Well, Brandon, where do people find. So why don't you tell us a little bit about your YouTube channel? Because I think that is such a wonderful resource.

I want to be sure everyone is aware of that. Yeah. If you search by name on YouTube. Brandon Bieber, I have a unique name. You can find it. I make videos about miss informative videos every Wednesday, and if you want to see a video made, you know, put in a comment.

I do look at those and sometimes make it into videos. For instance, some people suggested doing videos on this. A new re myelinated drug in early animal studies, page 307.

And I did in fact make a video of that. And so I really do look at these comments and I make them for the people with Ms.. The community of people with Ms..

Okay. So we've got a YouTube channel. Do you have any other social media I post about Ms. Research on Twitter. You know, so if you search my name on Twitter, you know, if you want to kind of follow new news about Ms.

Research, you can find me there. Okay. This is wonderful. Thank you so much, Brandon. Good to see you.