Progressive MS? Recovery Is Possible! Transcript

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Introduction and recovery background

I am so grateful that you agreed to be part of the M. S and Neuroimmune Summit. I value our friendship. I think you have some incredibly valuable insights to share.

So would you please tell people, introduce yourself and explain why you have this area of expertize? Thank you, Dr. Wahls, for having me on the summit.

This is just surreal, and I'm so grateful to be here. Well, as Dr. Wahls said, I'm Dr. Folake Taylor, and I am a recovery expert and educator. My training is in internal medicine, but I leave with primary progressive multiple sclerosis.

And I have been able to recover from both physical and cognitive disability to where I used to be in a transport chair scooter, then a walker, a can. And now I don't even use any mobility device.

And I've also recovered from cognitive disability that caused me to start practicing medicine. And now what I'm doing is helping other people do the same.

Everything based on the foundations that Dr. Wahls, of course, laid for all of us follow. There is nothing, you know, we both internal medicine docs, we we were great physicians and then we got the real education of our lives that transformed everything.

And I appreciate that. We have a lot of folks with primary progressive M. S. who have severe disability and with secondary progressive M. S. who have severe, severe disability, who think like, okay, so walls recovered, but no one else really did.

But it sounds like you were very seriously disabled and you have really remarkably reversed your function. Yes, that is that is okay. So how did all this begin for you?

Well, I will say that I've probably always had missed symptoms because I cannot remember a time when I didn't have wrist pain and ankle pain, but mostly in my wrists.

And as a child, I was not athletic. I not because I didn't want to I didn't have the stamina to be.

Early symptoms and delayed diagnosis

So I just I just didn't do sports and all of those things. But the first time it really became a big deal was in my late teens. I was in the UK for the summer trying to do some summer jobs and my wrists started to really bother me.

I was also trying to take typing in night college and that was just a no. So I saw the doctor in the UK, they screened me, you know, for all the rheumatologic disorders and all of that, everything was negative.

And then at that point I was diagnosed with sinusitis, which of course, you know, just means inflammation of the tendons. And so there became what was really a lifelong disability, but I didn't realize it then, you know, wearing the wrist brace, avoiding certain things. And just by the time I was in my twenties in medical school, I was diagnosed with carpal tunnel.

Now we know all of that was a mess, but back then we thought it was carpal tunnel. I ended up having surgery on my left wrist, but it only helps the acute symptom where I was trying to lose function at that time.

Of course, it didn't help the chronic symptoms because I really didn't have carpal tunnel. I had a mess that was

being misdiagnosed. So at that point, I decided that I wasn't going to go into a surgical specialty because I didn't know what would happen with my fine motor skills.

And I've just really spent my life dancing around everything that came up and the progression was so slow. As is typical for PMS that I never had to go into the hospital for anything serious.

Like optic neuritis attack or a big flare or anything like that. It was just over the decades, symptoms kept mounting. I kept saying, Rheumatologist, we couldn't find anything wrong and it just continued like that pretty much.

So that's. That's really where I. Finally got the diagnosis. At what age? At the age of 40 to 43 is when I got the diagnosis. And what had happened was a month after I turned 40, you know, we'd gone to Dubai, met up with family and friends, had the time of my life.

Then we came back to the States and my herniated disc, unprovoked, no injury. And it was really strange because I was fit. I wasn't overweight. I worked out six times a week, so and my pain doctor kept saying, Yeah, this is around the time that people get that.

I didn't realize that the tightness that I've been feeling in my lower back for like a decade, which is why I actually worked out every day, I realized that was the deepest spasms from M. S.

that actually caused the herniated disc. I ended up having two surgeries in the same month because we had a complication of a CSF leak from the first one, and in that same year I became disabled.

That could never go back to full time work. I only went back to work enough days and it was three years after before I actually came up with the fact that I have PMS and it took me that long and I'm a physician myself.

But yeah. And this doesn't look the same in people of color. Yeah, let's talk about that. I know it's a very different experience. In. For African-Americans and Caucasians and African-Americans.

We have higher rates of M. S. than people of Asian descent. And I believe also Hispanic descent. So how was your experience likely different as a black person as opposed to mine as a Caucasian person.

For example, talking about the mode of diagnosis and how I actually got the diagnosis. The first neurologist I went to, he did a few MRI's here and there.

First of all, he was pretty sure it could not be missed because I'm sure he's looking at me. I'm thinking she's not a Caucasian female. You know, so he basically blew me off and I took myself to the MSI Center of Atlanta.

And I was so blessed to meet a really nice man who treated the person in front of him and not the textbook. Because what it was is I didn't meet the McDonnell's criteria, so what he had to do was rule out everything else that he could be because we couldn't rule in MSC.

Nothing came up. Even my lesions could have been migraines that weren't really they were underwhelming. They've always been underwhelming. And my lumbar puncture, all of those things were not very, very clear.

So he ruled out on fibromyalgia. Again, I did all of his esoteric tests. I wanted a biopsy to rule out show grounds.

Racial disparities in MS diagnosis

I say geneticist, to rule out a mitochondrial disorder. So it was you know, it was it was pretty dark. It it everyone was listening. This is probably also common for people with primary progressive M. S.

that it's a very hard diagnosis to make. And also, when you convert to secondary progressive M. S., we do that in retrospect when there's no more relapses.

But clearly you're getting worse every year, like, okay. And that happens somewhere between age 45 and 50. You had the relapses go away and all we're left is this slow progression.

And then, you know, I think it can be certainly very challenging for the black individual to get their symptoms taken as seriously. So you really need to advocate for yourself. Yes.

And what advice would you give the African-Americans who are listening? I would say get a second opinion if you need to get a third opinion. After I got my diagnosis, I ended up being the person who sent a ton of people to my doctor who could not get a diagnosis, but clearly had M. S.

and they weren't, you know, black a lot of them were Caucasian women as well. But people who just didn't fit the criteria or the doctor was just, you know, they had that one episode and the diagnosed them with CFS and then they're waiting for the next big thing to happen.

But they're basically disabled because they're getting, you know, everything is going downhill in that meantime. But the doctor is still waiting for the next big thing.

And that was another thing I realized. So what I would say is get you know, see other people. And if you're a person of color, if you're a black person, maybe even see either a black male specialist or see someone that sees a lot of black M. S.

patients. So they are familiar with how it can show up differently in us. That's what I would say. Yes. Yes. You know, again, everyone is listening. I want you to think about the program issues that I've talked about before.

We know if you have anxiety, depression, you're more likely to develop a neuro immune problem. If you have pain, any type of pain that is poorly managed.

Yes, you are more likely to particularly if it's getting it's not well manage is getting steadily worse as you were experiencing and keep like okay we're struggling we're struggling and it's impacting your daily life.

Yes. That is the time that I want you to be thinking. Is this a neuro immune problem? Is this actually a progressive M. S.? Because that is tough. Tough to diagnose.

No. How did you discover my work? And that's really interesting, because all those months when I was waiting on a diagnosis, there's an older lady who had been in a a Caucasian lady who had been in a writing group with who happened to have M. S.

as well. So she was helping me out because she'd had it for decades.

Diet changes and the Wahls protocol

And she mentioned your book. Funny thing is, she wasn't ever able to actually implement it, but she told me about it and I was like, I ran with it. And that was the first edition of your book then, because we're talking about 2016, you know, so I started to read your book and the first thing I did was the gluten.

And it was pretty clear that one of my most annoying symptoms, which was it felt like something was burning under my skin or pricking me under my skin.

That particular symptom was from gluten, and it was so amazing to see that once I quit gluten, that particular symptom went away. Now, okay. Let's let's stop.

So people may not know what what all gluten is, where it shows up in your food. So what were the things that you had to remove or replace. Anything that has wheat primarily and then also barley and rye, they contain gluten.

So you are most of the breads except it's gluten free and most of the baked goods really do contain gluten. And

then there's the issue of things that behave like gluten, which came along later on.

Okay. So so you're taking out the bread, probably the cereals, the pastas. Were you replacing them or would you just take them out and eat more vegetables.

Initially and was replacing them with gluten free alternatives, which back then they really didn't taste as good as they do now. So it was it was it was challenging.

And that would go back and forth and I would cheat and I would get sick and all that. But yes, that's how I started. It was by replacing them and then progressively I got to where I really stopped eating those kind of foods.

Anyway because I, I am on the world's paleo plus so, you know. Okay, so processed foods and all of that well. Why don't you explain what the was paleo plus is people may not know that term.

Yes well there's the diet is the paleo and because the paleo plus and the paleo plus is really a type of ketogenic diet in which you're eating a lot of the good fats.

You're not eating a lot of carbs except from your vegetables. And some fruit like berries, and you're eating moderate protein and it includes going into ketosis as well as implementing fasting.

And those really, really move the needle for me because most people do okay on the paleo but with PMS, what I realized was that everything I did, I needed to really push it to the extreme to get benefit.

And once I implemented the once paleo plus I got all those benefits that I talk about in the papers, my fatigue, my brain fog, just my quality of life in general, improved.

Excellent, excellent. You know, and again, everyone who's listening when we're young, our immune system is more active. We're more likely to have those episodes of worsening or relapses or flares, whether it's that you have a mass flare or a flare of lupus or inflammatory bowel disease or rheumatoid arthritis that also increase your pain, your anxiety, your mood problems.

So it's very similar to the mass flare. But as we get older in our immune cells, get older and more mature, they quit being so reactive. And then we're in the progressive worsening that is part of all of those neuro immune diseases, whether you have inflammatory bowel disease, systemic lupus or multiple sclerosis.

So once you began doing the diet changes, were there any other changes that you did it or was it just diet that got you out of that wheelchair? I did a lot of other things, and I want people to know that the protocol is not only about food, it's about all lifestyle change.

Some of the other things I did was I was taking supplements, high quality supplements. I implemented some biohacking, like the infrared, like the vibration plate and things like that.

The other things that I did was decreasing my toxin load, decreasing exposure to toxins. And of course, the toxins in my body. And I know that a lot of people do, okay, once they change their diet, they're able to detox.

But for me, I realized that I actually had to go the extra mile and do protocols of pharmaceutical grade supplements to be able to get some of the toxins out of my body.

So just an extra a lot of extra with this. You know, so the more seriously disabled you are, you're in a much bigger hole and it's going to take more more work to get all of our biochemistry and ourselves to work better.

If you have very mild disease, maybe two lesions in your brain, too small lesions. You had a bout of dim vision that is fully recovered, so everyone looking at you would have no idea that you have a neuro immune problem.

That's a small hole. Now, there's still probably a lot of biochemical problems you need to fix, but it's no, we're you

probably won't have to do nearly the amount of work that full like you had to do to get her recovery.

Now, I'm really curious. What so let's let's have you describe what your day, what your function was like at your worst. And what your function is like today so people can see the difference.

Lifestyle changes and functional recovery

And I'd like to know how long it took you to get from your neighbor to where you're at today? At my worst, I was home for three and a half months, recovering from a surgery that I should have recovered from within weeks.

Yeah. And gotten back to work and I would be in bed most of the day. There were days when I didn't have the energy to come downstairs and eat even though there was food and my husband would get home from work in his work suit, sit by the bed and feed me soup.

So that was probably at my worst. Bedridden? Yes, basically bedridden. And how how clear was your thinking. At that point? I my thinking was still okay.

I think I believe that my cognitive decline happened over the years. So at the beginning, it was more of a physical problem, so physical than cognitive. At the beginning.

Were you clear enough that you could practice medicine? After my physical problems got a little bit better, I was able to go back to work, but I could do like 4 hours a day.

And yes, I walked into work tired in the morning. You know, to be truthful about this, at 8 a.m., I was already tired. Yeah, I know how I remember those days.

Okay, so you recovered. You you got up so you could get back to work about 4 hours. Fatigue, the big disability, you're still mentally clear. And that couldn't you could walk fairly well.

Not fairly well. I was going between either using the scooter or using the walker. Okay. Walker Yeah. Okay. And then what can you do physically now? Physically now?

I don't use any mobility aid. I still have them, but not even the cane. I hadn't used that in quite a while now, and like I mentioned at the beginning, my cognitive state declined.

So much that I was diagnosed by a neuropsychologist with cognitive decline and I had to quit practicing medicine. But I've been able to recover a lot of that to where I'm now starting the business and trying, you know, working my way out of disability and all of that.

So starting in business takes a lot of cognitive work folks. So yes. So clearly, clearly we've turned that around. And so mentally clear energy is that good.

Energy is good. Energy is good. Honestly, what really move the needle with the energy was when I started the world plus that was the biggest shift in my energy.

And even the brain fog was when I made the shift and I you know, to to the wall spiritual plus with the intermittent fasting and time restricted eating and then the ketosis.

The keto is very powerful that way. No mobility. You're not needing the scooter. The walker, the cane. How? If you're I went for a walk. How far would we go? Oh.

Well, let me just say, a few months ago, my I went with my daughter to the what you know, to Comic-Con, which was at a big convention center in downtown Atlanta.

And I walked for hours and hours and hours in that big convention center without any mobility aids. That is

wonderful. That is just so wonderful. So inspiring.

How is your daughter? He is 15. What a what a fun age. And it's just so wonderful that you could be back fully in life with your family if you if you had not discovered my work, would you be able to do those things?

A No, I would not. One of the things that still hurts me when I think about it is I got really sick when she was six years old and it was like night and day because I went from this impulsive mother who was there for everything to always being on the couch at night and not being able to function.

And even when I was able to stop going to stuff, I would show up in her school with my scooter because I couldn't walk around the active, you know, for the activities and stuff.

So, yes, that is the part that really gets me is what we lost, what we missed out of because of my disability during those formative years. For her. That happened in my family as well because when my daughter was five was when I was diagnosed and by the time she was eight, I'm in the Talk-Line wheelchair and life is very difficult.

Yeah. You know, my kids talk now about how embarrassed they were to have me show up in my wheelchair. Clearly disabled. And that was difficult.

Hope, purpose, and how to connect

Now, fortunately, when they're in high school now it's you know, I woke up and, you know, I started walking and being back in their lives again. And so I'm just so glad that you are able to show up for your daughter's life.

Now, do you have any last words for are people with progressive members who are struggling to figure out why their terrible symptoms are not getting better?

And for our African American colleagues who may be struggling with symptoms that are not getting better or have M. S. and are having a hard time finding someone who can listen to them.

Yes. What I will say is when I talk about hope for PMS with a Wells protocol, I'm not just talking about the literal hope. I'm talking about something called help one person every day.

And this wants you to focus only on M. S. and only on yourself, and to the exclusion of everyone and everything else. And that is not good for you. You need to figure out a way to find something you're passionate about and realize your purpose in something.

It could be in the mass community. It could be in your child's school, it could be anywhere. But when you can incorporate some kind of service back into your life, it will turbocharge your healing as well, because it definitely did for me.

And so that's the other thing that I wanted to add. I have friends who are twins, twins coast to coast. They are in wheelchairs, but they are some of the most giving and kind and loving people that I know.

And they are still fulfilled because they are working so hard in the mass community and in general. So that is something that's very important. I love the twins.

I love their message and I agree. I think this may be the most profound part of our conversation is giving back. Yes. To someone outside of you is profoundly healing in no matter what level of disability that we have.

I completely agree with follow key. Find a way to give back and it will give you a lot of meaning. Yes. Okay. For looking. What is the. Wow. Well, how can people find you and what can you in comes.

Well, before we get to that, are you seeing patients and can they come to you? Are you back in clinical practice? I'm not back in clinical practice yet, but what I am doing is I am creating an online course.

I'm going to have a program where I can help people with all the things that I did to get better as well. My focus is on women with M. S.. Perfect, perfect.

And how do people find you? Follow you. My website is full. I can Taylor Indeed.com and an. Program for everyone. Else as in Frank Ocean Orange Allison Larry as an apple, k as an chi, e as an egg and then Taylor t y l r M. D.

dot com and it's similar on IG. It's for like a Taylor, M. D. as well is my handle on Instagram. So those are probably the best ways to find me. Well, this has been excellent.

I love the work that you're doing and giving hope to everyone. Progressive M. S. is very tough, but I've come back from profound disability for like, it's come back from profound disability, so you can have hope, too, that you too can come back even from profound disability. Yes, that is that is the message.

You can do it. And there's people out there that can help you if you need help. And another thing is for those people who only have the first edition of Dr.

Wall's book and you think that you don't need the new addition, I would say there is so much more in the new book that you need to get that as well. So that's another thing I wanted to say.

Oh yeah. So the new edition has the blue banner across the top, revised and expanded, so it's got about 30% new new info. That's about 200 pages. So definitely worth picking that up.

Thank you so very much, Dr. Wahls. This has been so real and I appreciate it. Any time I'm in your spare space. All right. Now, much love to you and your family and that 15 year old daughter.

Go have fun at the next Comic-Con. You two. Dr. Wiles, thank you.