



National
Multiple Sclerosis
Society

**MS Learn Online
Feature Presentation
A Conversation with Clay Walker: Part 1**

Tracey

Hi, I'm Tracey Kimball

Tom

and I'm Tom Kimball. Welcome to MS Learn Online.

Tracey

Those of you who are country music fans know that Clay Walker is one of the most exciting stars around. But many are surprised to hear that he is also living with MS.

Tom

In the first of a three-part special web-cast Clay and Dr. Patricia O'Looney talk to medical correspondent Kate Milliken about the importance of early treatment.

>>Clay Walker [video]: "I made the mistake early on when I was diagnosed with MS of going into what I call a cave and really not living life to the fullest. I started giving up things that I truly loved, and those were physical things -- playing football with my buddies, basketball, playing golf, the athletic things. And now I'm back on track and I feel so blessed and so good that I don't think anything could stop me the way that I feel right now."

>>Kate Milliken: It has been observed that over the last 15 years, since the introduction of disease modifying therapies, that the number of benign cases of MS has doubled. Patricia, I think this is such an amazing statement to

start this whole webcast with, and I think it's important everyone understands what that statement means. So, what is benign?

>>**Dr. Patricia O'Looney:** Well, Kate, benign MS is really -- you think of multiple sclerosis and you think of benign, you think, well, everything is good. And that's basically what it refers to. It refers to defining someone who has multiple sclerosis and who is doing well walking. And so in terms of how the distance one can walk without any assistance, in terms of a cane or some other means. And so you look out over 10 years and you say, well, how good is that person doing with their disease in a 10-year period?

And so the name "benign" is probably not the correct term to use, but that's what the medical community has adopted, to refer to someone who is doing well after 10 years. But even within the medical community there's a debate on whether or not it's 10 years or 20 years, because unfortunately we don't have a predictor. So, when someone is diagnosed with MS, like today, there is no way to predict how that person will be 10 years or 20 years from now.

And so it is exciting news, because where we are today is incredible. We can actually look at data that we've accumulated over these past 10, 15 years, and we can ask the question, "How are people doing on these disease-modifying therapies?" And the report that you're referring to came from the New York State Consortium of MS Centers, and they actually do look back to 1996 versus today, over this 10-year period, and they show that there is doubling the number of people who had this benign MS, who are doing well.

>>**Kate Milliken:** So, it's not moving rampantly.

>>**Dr. Patricia O'Looney:** That's right. The disease is stabilized and the people with the disease are doing well after this 10-year period.

>>**Kate Milliken:** Clay, talk a little bit for you about your early treatments.

>>**Clay Walker:** Well, when I was first diagnosed with MS, I had no idea what it was. I thought it was MD, because I'd never heard of multiple sclerosis. And hearing those words that you have MS, I immediately pictured myself in a wheelchair. I didn't know what was going to happen. And the doctor who diagnosed me originally was a neurosurgeon, not a neurologist, and even he didn't have all of the answers. He thought that I would not live a long life and he relayed that to me. And so I was

devastated in the very beginning, but like people should do, I started seeking out what could I do for the disease.

Where to get information is very important because, obviously, if I had never heard of the disease, I didn't know anyone who had it, so I didn't know who to go to. And like you, I went to the National MS Society's website and found a lot of information.

But the most important thing that I did was find a great neurologist who specialized in multiple sclerosis, and that was the start of me getting on a therapy, Copaxone, which I've been in remission for over nine years now. And to say that, if you would have told me that when I was first diagnosed, I would have went -- the doctors are saying that's not going to happen, these people are saying it's not going to happen. But it did happen, and I think now more and more that not only our researchers but our doctors, the great neurologists, like Dr. O'Looney, they realize that we have hit some strides with MS that we didn't foresee 20 years ago.

>>**Kate Milliken:** Well, I think one of the things, too, it's wonderful that you actually went and the doctor said here's a therapy that works for you. But I can say from my experience, too, I was so surprised that there were so many choices. So, can you talk a little bit about some of those options?

>>**Dr. Patricia O'Looney:** That's a key word, Kate, actually, is the word "option." Prior to 1993, when the first drug was approved for multiple sclerosis, there wasn't anything. And so when someone was diagnosed with MS in 1990 or in the '80s, there wasn't anything. The good news today is that there are options, and there have been six drugs now approved by the FDA for the use for multiple sclerosis.

And no surprise, the theme across all of these six drugs is controlling the immune system. We do know and there is certainly strong evidence that the immune system is misdirected in multiple sclerosis, is causing an inflammation. All of these drugs are focusing on trying to control the immune system, controlling inflammation.

There are three different types of interferons: Betaseron, Rebif and Avonex; and, of course, Copaxone, Novantron, and most recently Tysabri. And so all of these six drugs are trying to control the immune system and control inflammation.

>>**Kate Milliken:** And it seems to be working for many of us. Let's actually take a question from the audience. We're going to Dare. Dare, cool name, by the way. Let's hear your question.

>>**Dare:** Well, first of all, thank you so much for your time, commitment and dedication to finding treatments. I was reading, actually, on Band with MS website that many patients are reluctant to report the disease, and that often there's uncertainty in diagnosis. So, I was wondering if you could explain why that would be?

>>**Clay Walker:** Well, I'd probably like to direct that question to Dr. O'Looney, who would probably answer that a little better. But I think one of the things is finding a neurologist who is an MS specialist, and those guys are not -- they're not a dime a dozen. There are not a lot of them, but it's important to get in to somebody who understands the disease and who is on top of the therapies, someone who is on top of what's on the cutting edge. I mean, your general practitioner can't really truly diagnose and take care of you as well as a specialist; am I correct?

>>**Dr. Patricia O'Looney:** Absolutely. I just echo Clay. No one should be hearing the words -- they've been diagnosed with MS and hear from the doctor, "There is nothing I can do." So, no one should hear those words. They should get in touch with a neurologist who is familiar with MS.

And then because of the options, try a therapy that works for you. Obviously with the different options, there are different modes of injections and frequency. And so in working with a neurologist and your doctor, you can find a therapy that works for your lifestyle, that works for your disease course. But no one should hear the words, "Oh, there's nothing I can do for you, go home with multiple sclerosis." That certainly is not the case.

With regard to diagnosis, one of the major revolutionary advancements in MS research in the past 15 years is the MRI. It all goes hand-in-hand: the therapies, earlier diagnosis primarily because of the use of MRIs, and just a neurologist.

>>**Clay Walker:** And also sticking to the therapy is really important. Mine is kind of easy to stick to because it's a daily injection, and so I know every day at the same time I have to take it. But it's important to give the therapy a chance. I would say at least a year to let it get in your system and to help you.

For me, I've been able to manage it and basically arrest the disease. I have had no new activity on my MRI for almost 10 years. Every therapy isn't going to work for every person, so getting with the MS specialist, neurologist, is what's going to really -- you're going to work out a program that works for you.

>>**Kate Milliken:** Yes. I also just say very quickly that I think some people don't go because it's scary as hell. I mean, we can -- both Clay and I, I'm sure, can relate to the moment of getting diagnosed and being freaked out. And I think there's a moment of reality of when you go to a doctor that this is really happening. But the great thing about it is that what you're getting from these neurologists and the medication is something that will make a difference.

>>**Clay Walker:** And, Kate, I think one problem that I see in MS patients, and this is very important to listen to. When you have relapsing-remitting multiple sclerosis, it remits, it goes into remission, and then it relapses and it comes back.

A lot of people who I've met have made the mistake of having an attack and then all of a sudden they get 95% of their mobility back and they're like, "Oh, well, I guess I probably don't have MS," or, "I guess it's going to leave me alone." That's the scary part, is that all of a sudden you feel normal again. But if you don't take that moment to go and get on the therapy, that next attack may do damage that really debilitates you.

So, I'm encouraging anybody who is out there to get on the therapy and to stick with it, and to get on it early. That's the best -- I think Dr. O'Looney would agree with me, that -- and I've heard this from several neurologists, having the advantage of being around doctors and researchers, because I've been so involved in the National MS Society and our own foundation, Band Against MS. I've been able to find that information, and that's the biggest problem, is that people don't get on it early.

>>**Kate Milliken:** Yes, absolutely, proactive.

>>**Dr. Patricia O'Looney:** Yes, I don't know if you want to talk about that, because that is an important plan and I certainly echo --

>>**Kate Milliken:** Sure. Let's get on to the next question, but we will come back, because I think that is really important.

>>**Dr. Patricia O'Looney:** Okay.

>>**Kate Milliken:** Okay. So, this is from Cherokee, from the Internet, who says to Clay --

>>**Clay Walker:** Cherokee?

>>**Kate Milliken:** Cherokee loves your song "Fall."

>>**Clay Walker:** I love Cherokee!

>>**Kate Milliken:** She's a big fan of your song, "Fall," and she says, "I was wondering if MS has had any effect on your singing or voice projection in any way?"

>>**Clay Walker:** Never. I've never -- I've met people -- one of my good friends, Richard Cohen, who is married to Meredith Viera, and he has written books. He's an esteemed book writer. His voice is -- you can barely understand him most of the time. And so I think that is the tricky part about multiple sclerosis. This isn't like pinkeye or a cold, where everybody's nose is running. Multiple sclerosis is the Houdini of diseases, because it can affect any extremity; it can affect your vision, your speech. You don't know what's coming next.

So, even more importantly, I still stress the fact, get on a therapy early, because that was my biggest fear, was that it could take my voice away. I was like, "Oh, no," and the symptoms I had were drastic, but fortunately never has it affected my voice.

>>**Dr. Patricia O'Looney:** And maybe I should add, it generally is true that there are no two people with MS that are exactly alike. I mean, this is the unpredictability --

>>**Clay Walker:** Are you saying we're special?

>>**Dr. Patricia O'Looney:** You are special. And I'm between two special people here.

>>**Kate Milliken:** Thank you!

>>**Dr. Patricia O'Looney:** But it is true. So, no two people with MS are exactly alike. Their course may be different, they may respond to therapies differently, but, yeah, it's just so important.

>>**Clay Walker:** This is so neat, Patricia -- can I call you Patricia?

>>**Dr. Patricia O'Looney:** Absolutely.

>>**Clay Walker:** That I'm a sitting --

>>**Dr. Patricia O'Looney:** And I'll call you Clay.

>>**Clay Walker:** I'm sitting here being interviewed by a woman, Kate, who has MS. I've never been interviewed by someone that I know of who had multiple sclerosis, and you look like you're doing wonderful.

>>**Kate Milliken:** Thank you.

>>**Clay Walker:** Some people ask the question, "Well, who is more likely to get MS?" And the truth is, you look like you're in perfect shape, and I'm almost perfect, but let me turn that question around to you. And I know that you're on a therapy from speaking earlier. What information did you get that started -- to put you in that direction and made you make that decision right away? Because it took me a year.

>>**Kate Milliken:** No, everything for me actually was very quick. And for me, in my psyche, I wanted to get on the medicine as fast as possible. Instead of being something that scared me, it made me feel better to know I was in really good hands. I do believe this whole society and the medical community is unbelievable. So, it actually, for a feeling of control for me was a good one. And thank you for the compliment.

Okay, onto the audience. We're looking for Lisa, who has a question, I believe. Lisa.

>>**Lisa:** Hello. Hi, Clay. Hi, Dr. O'Looney. I was wondering if you could give us the most recent update on Tysabri, because I know there were some troubles with that, and I know it's back on the market.

>>**Dr. Patricia O'Looney:** Well, you know, it's interesting. We're approaching almost the second anniversary now of Tysabri being returned to the market, and there are approximately 17,000 patients who are on Tysabri. The results are very good. Obviously, the data that they found during the preliminary work in the clinical trials is still upholding. So, in terms of how much relapses have been reduced and, of course, there have been no more PML cases that have appeared.

Keep in mind, of course, when Tysabri did return to the market, it was as a monotherapy, and also to be used in secondary therapy if other -- if people failed from one of the other primary therapies, like the interferons or Copaxone. But the 17,000 people who are taking, obviously people with MS are taking Tysabri, and we're collecting a lot of information.

One of the interesting findings that came from the Tysabri story has actually been required by the FDA, is to look at the quality of life. You know, we're so often talking about reducing relapses and slowing progression of the disease, which is also very important. But what about the quality of life?

And so there was an analysis of people taking Tysabri and it showed that there's an improvement. It kind of goes back to being proactive, how a person feels when they're taking a therapy. That's something we can't forget is how taking a therapy actually improves the quality of life for a person with the disease, in this case MS.

>>**Kate Milliken:** And we both feel that way, too. A question actually from the Internet from Penny for you, Clay. "I was diagnosed two years and four months ago, and I have not taken treatment, but I know I need to. I remember reading your story and your comment that, 'The worst thing you did was nothing for two years.' I told myself I wouldn't do that, but here I am. My question is, how can I get there, as you did, and take the meds?"

>>**Clay Walker:** Unfortunately, I was misguided in the very beginning of being diagnosed. My first neurologist -- and remember, this was in '96, so this was just shortly after therapies even really got started -- and he didn't recommend anything for me. He said we're going to watch it. You know, I can tell you right now, if you were sitting -- if you had 10 MS specialists sitting up here, you would not hear that out of one of their mouths, because we know the therapies work now.

So, for a year I just kind of was like, man, I know that I need a second opinion. So, I went to Vanderbilt and saw Dr. Sriram there. He said, "You have got to go on therapy right away." He didn't give me a choice. He was like, "We are going to do this." And it wasn't because I was relapsing; it was because he knew that I needed that protection. And I'll say this. Most people do not get on the therapy because of needles. They're scared of needles.

But what you have to weigh is this: For a few seconds of a little prick versus a lifetime of debilitation, which one do you choose? I don't think it's very hard to make the decision.

When I first started taking Copaxone, it hurt my first two weeks. But then your body accepts it and bam! there you are. It's like a diabetic shot. It's hardly anything at all. But you have to start somewhere.

I remember calling my doctor going, "What the heck?" And he goes, "Stay with it, trust me. Give it a few weeks; you're going to see a complete different reaction." And it was. I needed that guidance, though.

>>**Kate Milliken:** Didn't you feel, Clay, when you started taking the needles and starting the shots, didn't you feel a sense of empowerment?

>>**Clay Walker:** Yes, immediately.

>>**Kate Milliken:** Was there something that you said, okay.

>>**Clay Walker:** Immediately I felt that, and the number one thing was, I have two little girls, and if you have kids, your worst fear is that they are going to have to watch you go downhill. And I just remember sitting there thinking to myself, watching them play, I remember thinking, "How am I going to walk them down the aisle?" And that became my motivation.

So, what was really cool, too, is that they started giving me the shot, giving me the daily injection. I was like -- as long as they weren't fighting over who got to do it, you know, it was fine. But it was an empowerment not only for me, but it was letting my family see that I'm doing everything I can to take care of myself. And that's all anyone can expect from you.

So, if you do not get on a therapy and you have -- you start having debilitation, you're going to regret it. If you are on therapy and you relapse

20 years from now, you will know I did everything that I could do for it. So, that in itself is enough reason to get on it.

But, you know, here I am 12 years later, I'm still golfing, I'm riding cutting horses, I'm playing basketball, I'm exercising, and that's not -- I'm not bragging; I'm saying you can do it, too. You're a rock-climber. I saw your little bag, your hook. Are you going to give up rock-climbing?

>>**Kate Milliken:** No, absolutely not.

>>**Clay Walker:** There you go.

>>**Kate Milliken:** So, Patricia, give us a little recap of this first section, because I think we've gotten through some stuff that's worth taking away here.

>>**Dr. Patricia O'Looney:** Well, I think the single message is to try and be on therapy. So, if you're diagnosed with multiple sclerosis today or next week or a month from now, you certainly should be on a therapy. And there are options available. And the data clearly shows -- I mean, going back to what I said earlier, we've now accumulated 10, 12, 15 years of data. And we even have information when someone has been not even completely diagnosed with MS, but have a hint that they have MS, and we follow these patients on therapy, and there is really no question that the therapies slow progression of the disease. They're not a cure and they don't stop progression. Someone once told me, taking these therapies is almost an assurance that you're going to stop progression or slow progression.

So, while we're focusing on MS research and doing research on a cure, and trying to stop this disease, is so much better to try and slow the progression and keep the disease under wrap, so-to-speak, while we're still trying to find that cure.

>>**Clay Walker:** And to echo her about the cure. Having it for 12 years, I've watched doctors go from saying, in my first 10 years of having MS, Dr. Jerry Wolinsky, who is one of the leading researchers, Dr. Sriram is one of the leading researchers, Dr. O'Looney, who also is. I've watched those doctors go from saying we might not have a cure in your lifetime, telling me this, but we're definitely going to have something that we feel like will arrest the disease. I'm like, "Okay. If we arrest it at the stage I'm at now, I'm okay, I'm happy with that."

And so I think that we've pretty much done that with me right now. But then in the last two years what I'm hearing is something totally different. They're saying we are on to some things that we may very well be a cure in five years.

So, that's even more of a reason for the people who are watching today in our audience. That's even more of a reason to get on one of the therapies today. Hey, you've only got to do it for five years, it looks like.

I can't stress it enough that I'm here today in Denver, Colorado, because I know what the effects of a good therapy can do. And I feel a duty, but even more so a passion, to get people out there to find the right therapy. I'm not just pushing Copaxone. I'm just telling you what worked for me.

But there are other people who have -- who are on therapies that Dr. O'Looney mentioned that are working for people. So, get with that MS specialist. Get your program lined up, stick to it, and stay tuned to our websites to bandagainstmms.org, and stay tuned to the National MS Society, so you can see what's happening on the cutting edge before you hear about it in the news.

>>**Kate Milliken:** Excellent.

>>**Dr. Patricia O'Looney:** And may I just add, if people are thinking, "Oh, gee, I don't really want the injections," sometimes a support group might help. So, they may want to contact their local MS Society chapter in their region, join a support group. And maybe here --

>>**Kate Milliken:** Who will also help you learn how to do it?

>>**Dr. Patricia O'Looney:** Yes, help you decide, gee, you know, you hear other people's stories like yourselves here, talking about injection and the empowerment. And maybe someone with MS needs to hear that, about, "Gee, I didn't think of it that way. I didn't think of that being such a positive outcome." So, I would encourage them to do that as well.

>>**Clay Walker:** Can I go off the path here and just ask Dr. O'Looney a question? And this is an opinion, obviously, that I'm asking you. While I was at Vanderbilt a few weeks ago, we, Band Against MS, presented them with a research grant for \$100,000 over the next three years. Not a lot of

money in the sense of how many millions of dollars get donated to research, but it started, planted the seeds for them to be able to do some things, and they're having great success with it.

He mentioned to me that the stem cell research from your own stem cells, that they're taking stem cells, that they felt like that may be something that's going to be really big in about five years when the FDA approves it. Can you elaborate on that at all?

>>Dr. Patricia O'Looney: Great question, Clay, thank you. And we often talk about stem cells and we talk about the injection of stem cells. But what's really exciting in the whole area of repair and protection in multiple sclerosis is that we all have our own stem cells. And I think this is maybe what Dr. Sriram is referring to.

>>Clay Walker: Absolutely.

>>Dr. Patricia O'Looney: That there are actually cells that make myelin, called oligodendrocytes. We actually have some reserves in our brain, and so maybe all that we need to do is stimulate them to do their own job, to do the repair.

>>Kate Milliken: You're going to have to be playing some more uppity music.

>>Clay Walker: That's what I'm talking about, the message of hope that goes along with what we're talking about. People are sitting there right now going, "Well, you know what, it's too late for me. I'm in secondary-progressive, or I'm in this," and, yes, there are some dire cases out there, but I'm still saying there is hope for the people who are even in those cases.

Tracey

It's interesting to note that even stars like Clay Walker have similar questions as the rest of us who are living with MS.

Tom

To hear more from Clay Walker, Dr. Patricia O'Looney and Kate Milliken, join us for part two of "A Conversation with Clay Walker," when they talk about how to get the most out of your MS treatment.

