



National
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Webcast Transcript

Living Well with MS: Lifestyle, Diet and Complementary Therapies
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Moderator: Kate Milliken

Panelists:

Dr. Brenda Banwell, Division Chief, Neurology, Professor of Pediatrics (Neurology), Children's Hospital of Philadelphia, University of Pennsylvania

Dr. Allen Bowling, Medical Director of the MS Program at the Colorado Neurological Institute (CNI), Clinical Professor of Neurology at Univ. of Colorado

Dr. Timothy Coetzee, Chief Research Officer of the National MS Society

Dr. Albert Lo, Associate Professor of Neurology and Epidemiology, at Brown University; Associate Director of the Center for Neurotechnology and Neurorestoration at the Providence VA and is Director of Neuroscience Research at the Mandell MS Center at Saint Francis Hospital, Hartford CT

Kate Milliken: This is Living Well with MS -- Lifestyle, Diet and Complementary Therapies. I'm Kate Milliken, your moderator.

Multiple sclerosis is a disease whose symptoms range from numbness and tingling to blindness and paralysis. So it's unlikely that we'll ever find a one size fits all approach to living with MS. However, we have come a long way since the days of 20 years ago when people were diagnosed with what was considered an untreatable disease and sent home to rest.

Today, the most common form of MS, relapsing MS, can be treated clinically with 10 FDA-approved therapies. Still, living well with MS also means understanding strategies that enhance total health and wellness.

They include strategies that maximize productivity and independence, as well as strategies to help deal with the emotional, social and vocational challenges.

In this webcast we'll focus on what living well with MS may mean to people living with all types of MS. For me personally, living well with MS has meant balancing what I want to do with what is good for me to do and I am constantly gaining perspective.

Today we're here to address questions that we know matter to our viewers. We have already received nearly 1,000 questions from you, many of which we will discuss today, including applying a holistic research approach to stopping MS, restoring function and ending MS forever, examining risk factors for MS progression, combating cognitive challenges, exploring Vitamin D, oral antioxidants and dietary salt effects on MS, exercise and rehab strategies.

To help us explore these topics, I am joined by four panelists who recognize the importance of living well with MS. Let me introduce them.

First, we have Dr. Albert Lo. Dr. Lo is an Associate Professor of Neurology and Epidemiology at Brown University, Associate Director of the Center for Neurotechnology and Neurorestoration at the Providence VA, and is Director of Neuroscience Research at the Mandel MS Center at St. Francis Hospital in Hartford, Connecticut.

Dr. Lo is studying the impact of MS on employment, interpersonal relations and daily living, and is currently investigating robot-assisted neurorehabilitation to improve gait.

Dr. Lo: (nods)

Next, we have Dr. Brenda Banwell. Dr. Banwell is Division Chief of Neurology and Professor of Pediatrics Neurology at Children's Hospital of Philadelphia and the University of Pennsylvania. She focuses on the cognitive, emotional and imaging changes in pediatric multiple sclerosis.

Welcome Dr. Banwell.

Dr. Banwell: Thank you.

Kate Milliken: And welcome, Dr. Lo.

Dr. Lo: Thank you.

Kate Milliken: Next, we have Dr. Allen Bowling. Dr. Bowling is Medical Director of the MS Program and Director of the Complementary and Alternative Service at the Colorado Neurological Institute, and a Clinical Professor of Neurology at the University of Colorado. He has been involved in research related to nutrition, dietary supplements and other unconventional therapies.

Dr. Bowling: (nods)

Finally, we have Dr. Timothy Coetzee. Dr. Coetzee is the Chief Research Officer at the National MS Society. Dr. Coetzee leads the society's global investment in MS research. He is responsible for a diverse portfolio of research initiatives and recently spearheaded an effort to establish a global collaborative focused on research in progressive MS. So, hi, everyone.

Dr. Coetzee: Good to be with you.

Kate Milliken: So, Dr. Banwell, why don't we start with you. I'd love to hear a little bit about the research you're doing to help people live with MS.

Dr. Banwell: Okay. Well, my research focuses on pediatric MS and so our first initiative was to learn what MS looks like in a child and how to best make the correct diagnosis.

My colleagues are now looking at ways to treat MS in children. Specifically looking at safety benefit and pediatric-specific impact of medication. Finally, we're particularly interested in what children are going to teach us about MS.

The onset of MS in a child occurs at a very early stage of MS and our research is trying to understand what the earliest effects of MS are and what the earliest biological processes are that may get MS started.

Kate Milliken: Dr. Lo, tell us what you've been up to.

Dr. Lo: So a couple of big areas, one is neurorehabilitation. An area we look at is ambulation, gait and balance using robotic techniques. We're starting also to look at upper extremities and how impairments with the hand and arm can affect a person's ability to do everyday activities of daily living.

Another large area is the Rhode Island MS study, which is really focused on independent adult living. Patients tell me all the time they're worried about employment, taking care of themselves, and relationships with their family and loved ones. We're looking at all those aspects in this large epidemiological study.

Kate Milliken: Dr. Bowling, you have been involved with complementary techniques for over 30 years. How might this approach enhance a person's time with MS?

Dr. Bowling: There have actually been quite a few studies in this area, looking at the safety and effectiveness of these different complementary or unconventional approaches. There have actually been studies in people with MS showing that half to two-thirds are interested in and/or use these therapies.

It's very helpful to try to identify those therapies for people with MS that may be low risk and potentially helpful and then on the flip side, identify therapies that have been shown to not be effective or have been shown to be unsafe; so kind of highlight which are potentially worth pursuing and which should be avoided.

These therapies can potentially help slow down the disease, help with the symptoms, and overall just improve general quality of life.

Kate Milliken: I have to believe with people beginning to kind of look at how these therapies can be tested and figure out how to benefit people, the National MS Society must have some initiatives happening?

Dr. Coetzee: Sure, Kate. That's the really important part of what we do is fund the cutting edge research and some of the work Dr. Lo references is being funded by the (National MS) Society.

There are other things we're doing around lifestyle and diet. For example, we're taking a look at whether or not cholesterol could be tied into and be predictive about what's happening with MS progression.

Another case is we're examining Vitamin D, and looking at what role does Vitamin D play and could it be potentially used as an add-on to existing therapy.

We are also looking at a medical food product that could be tested in a clinical trial to see whether or not it helps with memory and cognition. I'm also excited about the kind of work Dr. Lo is doing with his robots because it can really pioneer a way for using technology to enhance the life of people with MS.

Kate Milliken: Sure. When you hear the word "robot," you think of machinery that, arguably, has nothing to do with a person with MS. So what is the connection?

Dr. Lo: Let me describe this a little bit. These robots are not R2D2 that come up to you, they're basically a motorized treadmill. There's a body weight support system and the person stands on the treadmill and the exoskeleton comes up behind them. We had the opportunity to test this equipment about 10 years ago. It was built in Switzerland and mostly used in spinal cord injury and stroke and never tested in MS.

So we decided to test it and what we found was you could certainly, indeed, improve people's walking speed and their endurance. When we looked at the quality of life, it decreased pain, it decreased fatigue, improved life satisfaction and also the physical component.

A couple of really interesting things also came up. The fastest speeds are not necessarily the ones the patients like the most and so the quality of their walk becomes very important, so we're looking into that.

We also discovered that exercise is incredibly important but these machines weigh about two tons so we're beginning to explore other ways they can do things at home and outside the laboratory.

Kate Milliken: You're not taking the robots home?

Dr. Lo: (Laughter) We're not taking the robots home. We can, but they weigh two tons.

Kate Milliken: (Laughter) All right. You need some big muscles. So from your perspective, how much is exercise important to a person's general health?

Dr. Lo: I think it's very clear that there's a response from exercise and decreasing other health problems, as little as 60 minutes a week can decrease your chance of cancer, diabetes, dementia; so it's very, very important -- that relationship is very clear. For people with MS I think they need to begin to think about this.

An example of something we're doing, as different from robots as this is, the next topic is the role potential of dance. Can we use dance, which is a very social activity, to promote physical activity, engage people socially and also improve their gait and balance? This is an actual area that we're trying to make very scientific, sort of called a "prescriptive dance" so very protocol and people should be able to reproduce it.

Kate Milliken: Wow. You know, when I think about dancing, I think that there's a total fun element there that comes with it. If you're looking at doctors who are used to clinical research, I think it's very hard to prove whether or not the fun factor has anything to do with how people are doing.

I kind of feel like that opens up a little bit of discussion, all of you, how it's been for you to figure out ways to prove clinically some of these alternative techniques. Anyone want to comment on that?

Dr. Banwell: Well, in pediatrics, I think we speak about "fun" all the time because that's really how we engage our patients. In pediatric stroke research, there's no question that when something is more of a game or an activity, of course, the child will do it more, they recover more quickly. I think it's equally true in adults.

I think when you gain a reward from an activity, you see yourself get better at it, you gain that confidence and self-esteem that we all value and you really do get better at it.

I think that is just everyday experience of what therapy means in exercise, which is that the benefit from it starts to also be visible in multiple other aspects of your life as you move forward.

Kate Milliken: Anyone else?

Dr. Bowling: I think it's going to be a process of exercising the nervous system, it could become very regimented and really, I think, not fun for a lot of people who are going to a physical therapy center, maybe doing something very regimented. So I think there's increasing recognition that for it to stick, for people to really continue with physical exercise, you really want to have a fun element and we're probably wired to have fun in some way in our lives and to have that fun connects us to some of these healthful activities.

There is a similar process with cognitive exercises. A huge emphasis now is to make those (cognitive exercises) fun because someone's not going to sit down for an hour a day and slog through laborious cognitive tests -- those same fun elements.

Dr. Lo: Let me add one more thing, Kate. I mean, this is the exact reason why we wanted to do this because the treadmill training is beneficial but kind of boring, there's a lot of treadmills out there as coat hangers. We acknowledge that the fun factor is part of the clinical trial because we want it to be effective and it's just too -- patients say, "It was so much fun. I like these people so much." Well, that's part of the intervention and we acknowledge that and that's kind of built into the study.

Kate Milliken: Sure and having fun, obviously, fights some things like depression, right? So what are some of the findings on depression that might help people with MS?

Dr. Banwell: Well, I think from my perspective, the first thing is to recognize that our emotional health and our physical health are all part of us. It is extremely important for people to recognize that this is not a separate entity. It is part of living with any human condition. Depression can happen and does happen frequently, even in individuals, of course, who have no other health concerns.

It is still something that is under-diagnosed and often not shared and discussed. I think depression can be a transient thing in someone's disease

course or it can become a major part of their disease course. In both situations, it needs to be addressed and managed. Management may or may not involve a medication, but it certainly needs to be discussed and cared for.

Depression can touch not only the patient living with MS, but their spouse, their children, their parents, even their best friends who may find it very difficult to see them have to go through MS. I think it is something that people need to talk about, get out there and deal with because it's treatable.

Kate Milliken: Have you seen a change over the years of your practice of people opening up more and it being more accepted?

Dr. Banwell: In our practice, yes, because we work really hard to bring it up early and in a way where we -- in my teenagers, for example, I'll say, "About a third of my patients tell me they feel really sad some of the time and their sadness stops them from doing something they wanted to do. Does that ever happen to you?"

I do that in an environment just with the teenager so that they feel they can share that and that's not uncommon. I would say that it is also very common for the mothers and fathers of my patients to endorse that this has been really hard on them and so we try to look at this as the whole family receiving care.

Dr. Bowling: I think something you touched on, which I think we as humans, I think we like to compartmentalize things and neatly divide them. We've got the mood state, we've got the physical state, cognitive function. The brain isn't that way, we've got these rough areas, but it's all richly interconnected. I must say, as a clinician, as I get farther and farther into being into clinical practice, it really is that compartmentalization seems very artificial and something that we have really created.

For example, I think some people you can see depression emerge when they start exercising less, almost like an exercise withdrawal syndrome bringing out -

Kate Milliken: When they stop exercising, they get depressed?

Dr. Bowling: Right or they get more fatigued, so there's a rich interconnection. I think you can -- those can play off negatively with each other but also positively.

Dr. Coetzee: I think that's what's changing about MS in terms of how we treat it and approach it is that we're looking at the whole person, not just one part of their life. I think that's one of the really important changes that's happening.

I also think that the work that Dr. Lo is doing with robots is also important because it's teaching us how other diseases and advances in things like spinal cord and stroke are benefiting MS and so being able to look outside of our own world is really also really critical.

Kate Milliken: In the subject of compartmentalizing, you know I think the 2,000 people who are part of this webcast watching would love to talk about the whole idea of separating clinical medicine and alternative or conventional therapies. At one point, maybe, Dr. Bowling, you can talk about what it was like for you 30 years ago to be in this world of non-conventional treatment and how it's changing and becoming less segregated in your own medical community?

Dr. Bowling: Sure. When I first got into this, I think many of my colleagues thought I had developed some kind of psychiatric condition and I'd gone a little loopy. Why was I reading about herbs and why was I self-educating myself because I hadn't actually learned any of these approaches in medical school.

That was even up to 10 to 15 years ago, really feeling it was sort of taboo territory. It was not an appropriate topic for, certainly, a program like this or any kind of public MS education program. It was really difficult to do this. It really just started one-on-one in my office.

I've actually been amazed over the past 15 years to see professional acceptance and professional interest in getting educated in this area. Something that was 100% of a lay education experience is providing us now kind of 50/50 between lay audiences and professionals.

It's been refreshing and I think that's opened this up to everyone wanting to know what is the evidence. I think that taps into we need to do research, and especially MS research to work this through further.

Kate Milliken: Dr. Coetzee, I would even say -- so I've been living with MS since 2006, right, and I feel having been in this MS world that there's been a

shift even in the past five years. My personal experience of coming up with something outside of my conventional therapy my doctors would say, "You can do whatever you want," but I wouldn't say it was widely embraced, to put it mildly. I think there's been a little bit of a shift of embracing the idea. Dr. Coetzee, maybe you can comment on that.

Dr. Coetzee: No, definitely there is. As Allen mentioned, there's a definite shift. People are looking at all these different areas as being potentially promising and telling us something about how people live with MS and manage their disease.

I think the key part has been to also think about it from a scientific point of view because we want to be able to understand what is happening and so funding some of the science and thinking what were the right questions, how to measure it, was challenging a few years ago. But now I think we have the tools to be able to understand and perhaps figure out whether or not a potential therapy -- how it's being beneficial and how it's helping somebody.

Kate Milliken: Is there an example, Dr. Coetzee, that you could give on something on the horizon?

Dr. Coetzee: Well, I think what I'm excited about on the horizon is rehabilitation exercise therapy because that has the opportunity to span across MS. So whether or not a person lives with relapsing MS or more progressive forms of the disease, you see, even in the conversation we're having, the possibility that we can improve cognition, help people with depression, help with physical mobility and improve quality of life.

I know in talking to people with MS that those small improvements in life really can make a huge difference.

Kate Milliken: One of the non-conventional things that have been coming down the pike is Vitamin D. Dr. Banwell, I'll throw this at you because, obviously, you've done a lot of studies with kids and Vitamin D. What are some pieces of advice or findings you might want to tell adults who are watching?

Dr. Banwell: Okay. Well, I think first, Vitamin D has been looked at in a couple of ways. There's been the initial investigations of Vitamin D related to the fact that multiple sclerosis is more common in certain parts of the world

than in others, it's particularly common in parts of the world where we have relatively little or less sunshine.

Our Vitamin D is largely made, normally, from the sun acting on your skin and leading to a process of Vitamin D production. We also get Vitamin D from the diet. One of the biggest changes that has happened in the last 50 to 100 years is the human diet. Not all in a good way.

When you look at those two things together, that drove a lot of questions. A lot of studies have shown that lower Vitamin D levels in the blood are particularly prominent in parts of the world where MS is common and that has led to the question whether having low Vitamin D early in life -- and particularly in my interest, of course -- in childhood might permit the immune system from making whatever mistake it makes that leads to multiple sclerosis.

It's not only MS, low Vitamin D, of course, has been linked to other diseases like Type I diabetes, a disease called Lupus and many others.

Then the next question also is -- that's before the disease is even known to exist, obviously, the next question is would giving Vitamin D slow the disease down in any way. There are some early studies that suggest that relapse frequency in MS patients may be lower if they maintain a healthy Vitamin D level.

The take home message for me would be that Vitamin D health is important to the population level. There are recommendations for daily ingestion of safe doses of Vitamin D for children and adults that have many health importance factors associated with them. For parents who have MS -- or for parents in general -- I think it's important to start Vitamin D nutrition in early life, to maintain it throughout life, to speak to your healthcare provider about what Vitamin D dosing is right for you, and to emphasize that Vitamin D in extremely high doses is, of course, not safe. There are monitoring techniques to make sure you're getting the right amount.

Dr. Bowling: I do think with Vitamin D and the studies we have now are really association studies, showing low Vitamin D associated with risks for MS and associated with increased risks for attacks. What is coming along now, I think funding from the National MS Society and other organizations, are the very important intervention studies -- if you give people with MS Vitamin D, does that change the course relative to giving them a placebo.

Those studies are just starting to come out. It's too early to say if there's definitely that causal connection.

Kate Milliken: Dr. Bowling, one thing that Dr. Banwell brought up was the whole idea of diet and everybody seems to be talking about diet in the world of MS. Why isn't there one diet that all of you very smart people can recommend for people with MS?

Dr. Bowling: I think that's a great question and it gets back to what we were talking about earlier, which is the evidence, that we don't have enough evidence. We don't have highly rigorous studies that show evidence for a particular diet impacting the course of MS like we do with MS medications.

The data that we have, the studies that we have, it's not definitive information. If you look at most people with MS who are interested in some kind of unconventional therapy, diet and dietary supplements are usually at the top of the list but then within medical practice, I think most MS clinicians don't really talk about diet that much. There is this split and it relates to generally we want our evidence to incorporate something into practice but then people living with MS understandably may want to use some approaches where there is not definitive evidence.

I think it's a matter of -- I think we need to come together and have information that's actually accessible to people with MS. Maybe it doesn't need to be part of clinical practice. But I think that's the place to come together in the moment. Then the way to come together definitively in the future is through studies to come up with something that could be incorporated into practice.

Kate Milliken: Of course.

Dr. Banwell: One of the other things is that even -- just like medications don't work exactly the same way in every person, what we absorb from our diet is in part influenced by what our diet has done before. So your body is very clever at absorbing what you need and relatively efficient at getting rid of things that we don't.

The same diet won't have the same effect in every person and so there may be very good reasons for that. I think we have to consider what nutritional needs

an individual person may have and that's not likely going to be the same throughout the lifespan.

I think that it's a fascinating question that requires careful thought. I think we can all identify things in the diet that probably don't help MS. We know that high cholesterol and early cardiac disease, just like it does in every other health condition, worsens any other condition the patient has. Developing diabetes and having multiple sclerosis at the same time -- it certainly worsens your quality of life and your health. A high salt diet may be one of the factors.

I think it might be easier to identify what diets we shouldn't be consuming and in so doing, we may actually come up with a diet that is actually generally more beneficial over all.

Kate Milliken: Dr. Banwell, can you actually -- talking about having diabetes and MS, or whatever, kind of talk about simultaneous things happening while having MS?

One of the things I know came up with the webcast questions was having a urinary tract infection in MS and how they affect each other. Can you talk about that?

Dr. Banwell: Sure, with respect to infections, or fever or coexisting illness, getting the flu -- all of us feel worse when we have an illness. We feel more tired. Our muscles are achy. We're more fatigued. We have maybe even a little bit of confusion if we have a bad flu. Those are the same things in multiple sclerosis patients but magnified. Your messages travel along your nerves at certain speeds. If those nerve pathways in the brain have been previously injured with MS, the messages go more slowly and so fever or illness can bring out symptoms in a patient with multiple sclerosis quite vividly. Treating the infection, then, of course, brings the person back to where they were, so it's important to know that.

Kate Milliken: One of the issues that have also come up is mental acuity and cognition. So whether it be dietary or anything else, I'd love to ask all of you whether you have any tips for people on how to sharpen their brains? Dr. Lo, do you have any thoughts?

Dr. Lo: Well, like everything in the body, we need to exercise it. So obviously reading and engaging in mental activities, educating yourself that helps.

Interestingly, exercise indirectly also benefits the brain. There have been studies in the elderly which showed that exercising merely 30 minutes several times a week actually increased the processing speed and memory considerably -- a significant amount. There are both direct and indirect effects from exercise.

Kate Milliken: Dr. Banwell?

Dr. Banwell: Well in my patients, of course, MS starts while they're still acquiring their fundamental building blocks of education. A big part of my job, and my colleagues, is to identify when children with MS are having trouble in school, to teach them differently and teach them to their abilities and to help them through what is often a very difficult period of time. They've just been diagnosed with MS. Now they're struggling in school and they don't even know if they'll go to college, which has been a life goal for them and their families.

Identify how to put in effective learning strategies, and there are a lot. We may not have time for, but there are some very effective learning strategies which are absolutely essential. I think the other thing I spend a great deal of my time on is getting the school boards to understand that you have to teach some kids differently. Children with MS may require some special help in school and be in a regular classroom but still need some extra help.

Kate Milliken: Dr. Bowling?

Dr. Bowling: I think really dissecting down what is causing the cognitive issues. You know, often if someone has MS and they have cognitive issues, it is related to the MS but there can also be other factors, especially depression. We were talking about depression earlier, really trying to identify if there might be some other mood issues that are going on.

Then also out of the complementary area, but prevention of cognitive decline - that's actually been shown with many of the disease modifying medications that we're all quite familiar with.

Also, I think there's a growing area -- I mentioned it earlier, but cognitive exercises, Dr. Lo mentioned that there's some preliminary evidence that some of these cognition enhancing approaches may be helpful to people with MS.

I know the approach 10 years ago -- do a crossword puzzle every day. Maybe that helps, but it helps to get better at crossword puzzles every day. The bigger question is what could you do every day cognitively that would then transfer into improved cognitive function in work or at home or your day-to-day life. That's a very active area using highly sophisticated software that could become individualized to the person doing the software and usually making that fun -- that's a very active area of investigation.

Dr. Lo: And speaking of that, Dr. Bowling, oftentimes talking about cognitive reserve, we're probably talking about neurological reserve or mood reserve, even. In preventing this, there's a lot of discussion about what can we do to prevent dementia or decline. Clearly, people, for example, who have a high level of education before they get older, they're at less risk for having dementia so this aspect of reserve is actually a very important concept.

Kate Milliken: Do you want to add anything, Dr. Coetzee?

Dr. Coetzee: It's great to talk about work that the Society is funding. I think what's important about this is the idea that we're looking for ways to get ahead of the disease. It's no longer sort of reacting to what is happening, but really thinking forward five, 10, 15, 20 years to really get to ensure the person gets the highest quality of life as possible. That's really why it's so important to fund some of this research.

Kate Milliken: Dr. Bowling, so now that CAM -- complementary techniques are kind of popular, what's trending? What are people into?

Dr. Bowling: You know the top of the list is almost always diet and dietary supplements. I think we've kind of covered Vitamin D and to me that's sort of at the top of the list. I think that whole topic kind of highlights is that unconventional or is that conventional? Some conventional physicians get offended if I put it on the unconventional -- so that just kind of -- it doesn't really matter. It's an area we need to understand. So that's kind of at the top of the list.

I think an area that sometimes is forgotten is Vitamin B12, the multiple studies (on it), this goes back many years now, but there's a subgroup of people with MS who are at risk for Vitamin B12 deficiency. Vitamin B12 deficiency mimics many of the symptoms of MS -- fatigue, cognitive difficulties, walking

problems and then I think everyone with MS needs to have a Vitamin B12 level checked. If it's normal, there's no benefit to taking extra.

The area that I think has dropped down some, but I still think it's not definitive, are polyunsaturated fatty acids, especially Omega 3 fatty acids. There are older studies with some suggested evidence, but then the best study ever done came out a year or two ago from Scandinavia and it was quite negative, but I don't think it's the final word. It wasn't the absolute perfect study but by my mind that's dropped down some on the list.

Kate Milliken: I would love just to ask you one quick question in response. When people hear about dietary supplements, you think about a person with MS who goes into Whole Foods and there's a whole aisle of vitamins. How do you make someone know what they're doing or give them counsel or simple advice on how to get what they need and do it safely?

Dr. Bowling: I think that whole area has changed. I think up until -- well, certainly, up until seven or eight years ago -- and maybe even up until a few years ago -- the thought was dietary supplements are either going to do nothing or they're going to be helpful. Then the humbling thing was starting back 15 to 20 years ago, some really high quality, huge number of people involved in these studies looked at very specific supplements in fairly modest doses, following up on studies done with foods that looked suggestive for a particular vitamin or mineral being helpful. What's been found in those studies are now at least 15 studies showing modest doses of some specific vitamins and minerals at pretty modest doses can actually have negative effects.

So it's not that it's doing kind of the shock approach where it's going to be neutral or you're going to get good effects. You have to be cautious with that. It's more like a single bullet approach and a very thoughtful about each particular supplement and how those are being used.

Kate Milliken: I know that you cannot prescribe on the webcast here exactly what to do but it is a tough situation, even to hear you say that some is too much and some is too little. Is there any simple advice you would give to someone trying to figure it out to do something right in terms of "get pro-DHA, get pro-EPA," and do it okay. Tim, you can comment, too.

Dr. Coetzee: Well, I'll let Allen talk about prescribing or giving medical advice. I think one of the good news piece though is that when it comes to

supplements and these types of topics there are -- we are doing some clinical trials now looking at things like antioxidants like folic acid to see could it have a beneficial effect of protecting the brain in a person with MS and looking at green tea extract to again see if it can protect the brain from damage.

These are small studies in people, in human beings but can these antioxidants mop up the free radicals that will damage the brain? These are the kinds of questions that we can start asking. I don't think 10 years ago we could really ask that question well but now we have the tools like MRI to be able to ask that question intelligently.

Kate Milliken: Go ahead.

Dr. Banwell: Well, I would make a comment on trying to understand -- as scientists, we always try to understand why. I think a great question to ask, whomever you're seeking advice from as to your diet or your supplements, is why do you think this would work for me.

If the provider that you're speaking with answer is, "Well, it really promotes the immune system, we think it's really great for your immune system," I would pause because we don't really want to turn the immune system on in MS. If anything, we want to dampen it or regulate it better.

If the answer that the provider has is it's pro-immune, I would ask another provider. I would seek a second opinion on that agent because, theoretically, if it does what the person is saying it's going to do, that could take you in the wrong direction. That's a very simplistic approach, but I think it's reasonable.

Kate Milliken: It's nice to have some guidelines as a patient, "maybe this is not good, maybe I should go a different path".

Dr. Banwell: I think the other part is I spend a lot of time with my patients and their families developing a relationship where they will tell me what they are exploring. We have found some things that interact with the other medications the person is on and therefore, instead of getting benefit from either, you're getting neither. Communication is really important. More is not better and there are a lot of times where too much is actually harmful.

I think the other final thing would be mechanisms. We've been talking about diet, we should also talk briefly about obesity. There are studies now showing

that if you're a heavier set individual in late childhood or teenage years, you are more likely to be diagnosed with MS later. Body mass index or your overall size has been associated with other autoimmune diseases and inside fat cells there's a vigorous immune system.

I think we need to think about why these relationships might exist and so back to just being a healthy diet, a healthy weight ought to be a really important consideration that affects your ability to exercise, it affects many other health components. We have an obesity epidemic in kids and in adults, I think, it's an important thing to think about, too.

Kate Milliken: One thing that I think about and hear about all the time is gluten. So who wants to respond to what gluten is?

Dr. Bowling: So gluten is actually a fascinating topic. I think it's going to be changed very much in the next three to five years. I think there's going to be major advancements in this area.

The one area that's the clearest is celiac disease, a very well documented sensitivity to gluten, which is the protein in wheat, barley, rye. That particular condition, celiac disease has blood tests that you can do, biopsies that you can do, there's genetic risk factors for it. It's a very well understood condition affecting 1% to 2% of the population. If you look at people with MS, most of the studies indicate it's 1% to 2% of people with MS who have celiac disease. So it doesn't look like -- from most studies, it doesn't look like there's an overlap.

The bigger question that we don't have the answer to at this point is non-celiac disease but gluten sensitivity, it's called non-celiac gluten sensitivity. That's a condition where people, when they ingest gluten, can have abdominal symptoms, bloating and discomfort or they can have other symptoms anywhere in the body. People with MS, by report, can have worsening of their neurological symptoms, a little like with the urinary tract infection, gluten can kind of bring out someone's vulnerability.

Gluten sensitivity has been hard to get a handle on. If you look at the medical literature on it, it's incredibly confusing because there are no diagnostic criteria. There's no way to diagnose this other than someone saying, "I have these particular symptoms when I take in gluten."

The next few years I think there'll be major pushes to have diagnostic criteria and even before the diagnostic criteria can come out, studies looking to try to define subgroups of people who -- what percent of people does limiting the gluten truly help them. The number now is 10% to 20% but we might find over the next few years that it's maybe 1% or 2% who do have some kind of non-celiac gluten sensitivity then maybe people who feel this sensitivity but we can't document any condition that's producing that.

This is all complicated by the fact that there's a very large food industry that's producing gluten-free foods.

Kate Milliken: But again, from a patient perspective, it's very exciting to hear. Uncharted territory has chaos but somewhere in it there are results. I feel like, Dr. Lo, with your experience with retraining the brain, that's an example of kind of a whole new domain.

Dr. Lo: Right. Well, I'll just respond a little bit about the diet, medications and supplements.

I think it's an exciting trend that we're starting to test this. At one point someone said there's no evidence. Sometimes no evidence is an easy and uninformed answer because there's no evidence meaning no studies have been done. What you may want to hear is people have done the best studies and we know it works or it doesn't work.

This is true of exercise and rehab as well. There have been very few large rehab trials where you're looking at retraining the brain. One of the things I've learned in medical school and as a graduate student is neurons that fire together wire together and that's one of the principles we want for exercise, repetitive training. We've shown in a different study in a population of stroke patients that if you train people, even if they had a stroke 20 years ago, you can actually regain significant benefit in that paralyzed limb.

Sometimes there's something called disuse atrophy and that applies to people with MS as well. If your leg or your arm has impairment, you stop using it more and that causes further decline in function, so you want to regain that through more rigorous kind of rehab protocols.

Kate Milliken: Sure. The other item that I wanted to bring out that I keep hearing about is the microbiome. So, Dr. Coetzee, maybe you could put that into context for people who have no idea what I'm talking about.

Dr. Coetzee: Sure, microbiome, my favorite topic (laughter). The microbiome is a fancy word that basically talks about all the bacteria that live within the human body. We have bacteria on our skin and a lot of it is in our intestinal tract.

As we've been trying to figure out what's happening in the intestinal tract and understand that biology, what we're beginning to understand is that there are good bugs and bad bugs. Sometimes the bacteria that are bad for us actually become dominant in the intestinal tract and that starts talking to the immune system and that starts a cascade that can actually be detrimental to a person living with MS or other autoimmune diseases.

Like exercise and rehab and many of these other things, there is a lot we don't know about the billions of bugs that live within us. The good news is that there's a lot of science that's being directed towards that, to try to get an understanding and even potentially the crazy idea that you could perhaps try to change the bugs that live within you to perhaps have a beneficial effect.

Dr. Bowling: I think it's potentially a very exciting area and has been hard to explore because many of the organisms in our gut live without oxygen. You take them out, they get exposed to oxygen and then you can't culture up the organism so there are very sophisticated DNA methods being used to identify what these organisms are.

I think in terms of MS-specific studies, some studies out of South America indicating when people with MS have fairly benign parasitic infections, they have less disease activity with their MS. Then some studies I'll talk gently about it, we're getting close to mealtime here, but using hook worms and whip worms -- some parasitic worm infections actually being induced in people that are benign parasitic worm infections don't cause major abdominal issues and some have suggestive beneficial effects coming out of those studies.

Then some early animal studies that are going to soon lead to human studies with very specific bacteria; some perhaps identified with these more sophisticated methods identifying bacteria that have a beneficial training effect on the immune system or a modulating effect on the immune system in the gut

that then translates into a modulating effect on the immune system in the brain.

Dr. Coetzee: In fact, we're funding that study at the University of Wisconsin. We're hoping that people with MS are taking these milkshakes with parasitic eggs and the idea is can this perhaps reprogram the immune system in a beneficial way. Hopefully next year we'll know the answer to that question.

Kate Milliken: So how do all of these studies and research fit into the MS Society's broader portfolio, Dr. Coetzee?

Dr. Coetzee: That's a great question because we have a big portfolio. You know it's focused in three areas -- stopping progression, restoring function and ultimately ending the disease forever.

For a long time we've been trying to understand how the immune system works and how the brain works. Now that we've moved to the place where we have a pretty sophisticated understanding of the immune system, we can then start asking these other questions like how does rehabilitation connect with the immune system and can exercise improve cognition? Can we have rewiring or reprogramming of the immune system?

It also fits in with things like Vitamin D, diet and exercise. You know, this issue of other things that people live with like obesity, cardiac disease, we're starting to think that those also affect clinical trials and the outcomes. So as we're trying to answer these questions about a particular complementary therapy, you have to stop and ask the question, "What else is going on in that person's life that could confound what we're seeing?"

We're all scientists here so we like cleanliness and precision but sometimes these other things just affect the trial in ways we can't appreciate. That's why we have to fund a broad range of research.

Dr. Bowling: That's sort of a trend within American medicine and research. I think for years there's been this idea where you go to the doctor in this sort of hygienic clinic visit and you prescribe medications. Then the person, for 99% of their life, is actually living this life that you have no understanding of as a clinician. Every three to six months, someone comes back and sometimes in a worse case scenario, they're having this awful lifestyle, awful diet, and they're getting diabetes and high blood pressure -- which they're doing here and then

they go every three to six months to get the pills to deal with the condition caused by the lifestyle.

I think what we're seeing is a bridging of these two together in a way that I don't think has ever quite happened at this level in American medicine or it's some sophistication to be able to understand the lifestyle and take it into the clinical practice.

Kate Milliken: And for you, who was deemed psychologically questionable, this is probably a very exciting time for you. (Laughter) You've turned out to be a trendsetter.

Marijuana. Who wants to take it on?

Dr. Coetzee: I'll take that one. People with MS tell us that marijuana can help them, oftentimes it's for spasticity, pain and fatigue. You know, there's a lot we still don't know about what's happening there. We are funding some clinical trials to understand how marijuana could benefit an individual, particularly when it comes to spasticity.

I think the important thing about it is that it does highlight the one big gap that we have in MS and that is in terms of helping people manage symptoms of the disease. We don't have very many tools and the physicians don't have any specific approved therapies for pain and spasticity and fatigue and so I think marijuana points out that there may be some benefit that we need explore in some meaningful way.

Dr. Bowling: I think this area is quite interesting. I've actually looked at the studies, kind of lower to higher quality studies of marijuana and marijuana-derived products. Actually, there are 19 studies out there of those types of therapies in MS. There are also 18 states plus the District of Columbia that have medical marijuana laws.

I think it's very difficult, though, at this point, in spite of these 19 studies, it's very hard to translate what's shown in those clinical trials with clinical practice. We've had medical marijuana in Colorado for more than 10 years and it remains a challenge.

Part of the challenge, as Dr. Coetzee mentioned, in terms of the therapeutic effects, most of these studies indicate benefit with pain, a person's sense of

their own muscle stiffness and sleep. The challenge is most of these studies have been done with standardized herbal extracts that are only available for research purposes or the single molecule in marijuana -- THC. What's happening in most medical marijuana states is availability to smoke marijuana or sometimes actually unregulated herbal extracts.

It's very hard to kind of blend those two approaches. I think we're all going to be obligated to have some meeting to work this through with these laws passing. We have Colorado and Washington, medical marijuana is sort of old news, now it's available at the recreational level and people are going to be potentially mixing it with their medications. How do you do that appropriately?

Kate Milliken: Dr. Banwell?

Dr. Banwell: Well, I just want to comment on the smoking versus extract or other ways because there's also some literature emerging on the detrimental effects of cigarette smoke, particularly, on MS outcome and disability. The biological part of that relates, at least in part, to what component of the immune system that exists within the lung.

My concern, particularly since I look after kids, is what the company of marijuana smoking may keep. The smoke component of it is one issue but I would be concerned, then, about promoting smoking in youth and young adults. I think the single biggest health advance of the next 20 years would be if smoking was actually really to drop dramatically in terms of all the other health impacts of smoking.

That's one of my concerns and I think -- I don't know if those two always go together but I do worry that they would potentially run together and the smoke effect would be a big problem. So looking at the components in marijuana and how they might work could lead, perhaps, to therapies that would have less health risks.

Kate Milliken: It's a very fair point, for sure.

Dr. Bowling: The whole trickle down to the adolescent population, that's of high concern. Then also multiple MS studies -- there are the general health effects associated with the marijuana potentially and then the MS studies --

several have shown cognitive difficulties in people who have MS and have a regular marijuana use.

I think it's important for people to know that now there are medical marijuana laws that allow use in MS that does not mean that the safety and effectiveness in MS is known. The only barrier up to now is just the legalization aspect.

Dr. Coetzee: It is one of those areas, that Allen pointed out, is to have a conversation with your physician if at all possible so that if this is part of an individual's life, that physician has an ability to understand and sort of work with the individual on it so that if there's an effect on their treatment or something is changing in their life, they can really see whether or not that's a factor in contributing to it.

Dr. Bowling: I will say I was happy the National MS Society let me do this, so I actually wrote an article for Momentum a couple of years ago on marijuana reviews all what we know and what we don't know. That's something we share readily in our clinic for people to actually develop a fund of knowledge concerning it.

Kate Milliken: Well, it seems there's a real shift -- of things moving forward and kind of new domains. One of the items that has yet to go away in the National MS Society is progressive MS. I want to believe with all this forward moving on the non-conventional side, you might have something to share on the progressive MS side?

Dr. Coetzee: Sure. Progressive MS is a priority for us and it is for many physicians I know who treat people with MS. They're very passionate about addressing progressive MS because of the challenge that we don't have any FDA approved therapies for it, now that's not for lack of trying. There's been a lot of trials of the existing therapies to see whether or not they work in progressive MS and they haven't as yet but there's more that are under way.

What we're trying to do is focus our efforts on understanding what is progressive MS. Some of the science tells us that there might be something different about the biology of progression and so we need to get a handle on that. That's why we have joined up with our colleagues in Canada, the United Kingdom, Italy and the Dutch MS Society, and actually a number of scientists around the world, to create the International Progressive MS Collaborative that is going to try to bring the world together around this problem because there's

a lot of science that needs to be done in order for us to get the therapies we need to tackle progressive MS.

Kate Milliken: It's fair to say that finding numbers of biological distinction in progressive MS was progress, right? It was a big deal.

Dr. Coetzee: Oh it absolutely was. Dr. Lo and Banwell were at a meeting that we held earlier this year just on the topic of progressive MS. We're starting to see an intersection of all these different areas. I think what excites me is that the progress we've made in addressing the needs in relapsing-remitting MS creates a pathway so that we can actually get past some of the barriers quicker in progressive MS.

Certainly, I think, Allen and Brenda, you might want to comment on what you saw in our meeting.

Dr. Banwell: Well, for me one of the things we've talked about is not 'siloing' our patients or putting people into compartments -- by compartment in terms of mental health or physical. In science, we need to recognize that there are many other neurological conditions that have a progressive component to them. The meeting that we were referring to included discussions of other progressive diseases, how they have explored that component of the biology, both from a clinical and patient advocacy perspective, and also from a scientific point of view.

I think one of the things that came through for me was the concept of what we're calling a cellular reserve. In other words, how much can a part of the brain handle before that part no longer works properly and the patient experiences a deficit. Understanding what makes a cell more resilient and what makes a cell more vulnerable can cross many different diseases. There were some very, very exciting topics being presented, I thought, in that domain.

There are some potentially therapeutic strategies there that might be very, very valuable and maybe we can partner with big groups that are studying other things and learn as a collective. I think that came through very well.

Dr. Lo: I thought it was an amazing meeting. It brought together an incredible group of investigators. Many I've not seen for some time, but they also brought in pharma, they brought in advocacy groups and all discussed what the barriers were to get a treatment for progressive MS.

I was in the rehab group and I think our group felt there was a lot of relevance in developing rehab and exercise for progressive MS, because that's actually one of the few interventions that's available for them.

We noted as a group there's been no great cognitive rehab study that's been done. There's been no great exercise study that's been done, so as a group, we're starting to actively plan on that.

I think one theme you're hearing here is, whether it's marijuana or Vitamin D, is that scientifically it's easy to prejudge some of these agents. From a scientific point of view, you want to look at the agents objectively, what's the mechanism, why do we think it works and test both safety and efficacy.

Also, we talked about implementation. You know, the group that runs with marijuana may not be the best. We can come up with the best intervention, but if it's impossible to administer, that's not going to be a great drug.

Kate Milliken: What I think is great is a patient says, "This makes me feel better." I do feel like there's a little bit of progression. I've got to believe for you guys it's been very frustrating sometimes to not be able to have the clinical evidence behind what you're working with and when someone says, "It does make me feel better," being able to move that forward.

Before we wrap up, I would like to ask each one of you what are you most excited about personally that's on the horizon.

Dr. Lo: I'm particularly excited about the fact we're making so much progress. Whenever we go to these meetings, I feel very excited about it. They really want to develop something, Relapsing-remitting, progressive MS...

Kate Milliken: And that's really true. You are making progress.

Dr. Lo: It's amazing. You kind of get motivated by that. I think in rehabilitation, one of the most exciting developments is probably combination therapies, probably combining a pharmacological agent or biological agent because I consider rehabilitation -- not only rehabilitation but repair, regeneration and restoration. What would have the best opportunity to rebuild the nervous system in the rehab setting?

So for example, one of the few medications out now is Dalfampridine. People are trying to combine that with exercise. There might be a better biological agent that comes out for regeneration, remyelination, we'd love to combine that with rigorous rehab protocols. I think that's really an exciting area for me.

Kate Milliken: Dr. Banwell?

Dr. Banwell: I think the most exciting thing I've seen the last few years is the removal of barriers to collaborative research. The branding of research having to be done in a given university or a given hallway or a given lab, has really changed to international consortia like the meeting in Milan where people that haven't seen each other, as we were saying, sat in the same room and said, "Let's get the best plans together and tackle this particular problem."

I'm part of the International Pediatric Multiple Sclerosis Study Group which started with seven of us at the meeting funded by the National MS Society a number of years ago and it's now 150 people in 40 countries that represent pretty much the majority of pediatric MS research collaboratives in the world. That is the way to go forward in my view.

I think this disease requires people to think broadly to incorporate alternate medicine providers and experts by experts with neurodegenerative disease experts and with clinicians who understand MS together. The groundswell toward that type of collaborative research to me is what's really going to move us forward.

Kate Milliken: Great. Dr. Bowling?

Dr. Bowling: I think the openness to looking at these unconventional therapies, like we've said that was not there 10 to 15 years ago, so there's an openness, there's very little of a taboo feeling about it, so there's an openness. Then many studies funded by National MS Society and other MS-specific studies looking at these therapies, the safety and effectiveness.

Then as we accumulate more information, I think that each step along the way, communicating the best we know to people with MS, so there can be MS-specific recommendations or MS-specific guidance on what types of therapies to avoid.

Kate Milliken: Dr. Coetzee?

Dr. Coetzee: So for me, on the science front, I am really excited about the research that's being done to rebuild the brain. Whether it's through rehab or through stem cell therapies or other types of strategies that can restore function and bring back what people have lost, particularly for those with progressive MS.

I'm also excited because it also is happening across the world and people are talking to each other whether it's in North America to Europe to Asia. This is a global deal and people are really working together in a meaningful way in ways that I think we didn't appreciate could happen even 10 years ago. I'm excited that the science is going to be conquered by the collaboration.

Kate Milliken: Wonderful. I want to thank our panelists: Dr. Albert Lo, Dr. Brenda Banwell, Dr. Allen Bowling, and Dr. Tim Coetzee for being here today and sharing their expertise with us.

I also want to thank you, our viewers, for joining us today. If your question wasn't answered, please speak directly to your healthcare provider or visit the Society website at nationalmssociety.org. You can also contact the Society's information resource center and speak with one of our MS Navigators at 1-800-344-4867.

As always, our webcast participants have submitted so many excellent questions that we've not been able to cover them all. Fortunately, our panelists have generously offered to continue the conversation over the coming days on the MS Connection online community blog. Be sure to visit MSconnection.org to catch their follow-up blogs and take the opportunity to connect with other visitors from today's webcast who want to share their own strategies for living well with MS.

Please note that today's webcast will be archived and available for viewing on nationalMSSociety.org. Thank you, and goodbye from New York.