



National  
Multiple Sclerosis  
Society

## Webcast Transcript

Working Toward Your Best Life: Advances in Quality of Life Research  
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### Webcast Moderator:

**Tracey Kimball** – Serves as a moderator for the National Multiple Sclerosis Society’s MS Learn Online program. She was a former theater, TV and film actor. Tracey was diagnosed with MS in 1995.

### Webcast Panelists:

**Dr. Dennis Bourdette** – Chair of the Department of Neurology and Director of the Multiple Sclerosis at Oregon Health & Science University (OHSU) and Co-Director of the VA MS Center of Excellence - West. Dr. Bourdette’s team has forged novel explorations of therapeutic strategies for MS including alternative therapies.

**Dr. Robert Motl** - Associate Professor of Kinesiology and Community Health and Director of the Exercise Neuroscience Laboratory at the University of Illinois at Urbana-Champaign. Dr. Motl is a published researcher in kinesiology and neuroscience, examines the relationship between physical activity and improved quality of life, and co-founder of the “Internet Physical Activity Intervention in MS Project”.

**Dr. Nicholas LaRocca** - Vice President of Healthcare Delivery and Policy Research at the National MS Society, clinical psychologist, and manager of the Society’s quality of life and symptom management research.

**Tracey Kimball:** Hello, and thanks for joining the National Multiple Sclerosis Society's live webcast -- Working Toward Your Best Life -- Advances in Quality of Life Research. I'm Tracey Kimball, today's moderator for the webcast.

I immigrated to the US from South Africa in 1985 as a successful theater, film, and television actress. From my childhood while I was studying acting, I was always fascinated with health and nutrition. I've grown up doing ballet, gymnastics and modern dance, eating very healthfully, and taking nutritional supplements.

Later, while I was working in Hollywood, I became a long distance cyclist, riding hundreds of miles a week in the hills around my home in Southern California; regularly scuba diving off the islands in Hawaii; and snow skiing in Utah. My love of a healthy lifestyle led me to a career change and I became a cranio-sacral therapist and moved to Colorado to open a practice devoted to that field.

I did continue hosting various television broadcasts, but the pull of the health and nutrition field caused me to return to school with the goal of becoming a psychologist. Then in 1995, I was diagnosed with MS after waking up one morning and finding myself completely paralyzed on the left side of my body.

After recovering and several months of physical therapy, I decided once more that I'd return to on-camera work where I've served as a spokesperson for a number of clients and organizations, including the National MS Society.

The topic of this webcast, looking at directions in lifestyle research, is personally very important to me because of my passion, which is to help people live the healthiest life they can. After everything I've been through in life, I'm learning still, too, each of us is unique and our bodies are constantly working on many levels to be the best that we can be; therefore, I am looking forward to learning special insights that each of our panelists bring to this issue today.

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've come a long way since the days -- less than 20 years ago -- when people were diagnosed with what was considered an untreatable disease and sent home to rest.

Today, we'll examine advances being made in such important areas as enhancing wellness through complementary therapies, managing fatigue, taming stress, and combating emotional and cognitive challenges. We've brought together three leading experts who have played a pivotal role in these realms.

We're really pleased that we've already received many questions related to such topics as the effect of heat on MS, the best way of staying active, how stress might relate to MS flare-up, brain fog, and the role Vitamin D might play in MS. Feel free to submit questions during the webcast and we'll do our best to get to as many as possible.

Now, let me introduce our panelists. Dr. Dennis Bourdette is Chair of the Department of the Multiple Sclerosis Center at Oregon Health and Science University and Co-Director of the VA MS Center of Excellence West. Dr. Bourdette's team has forged novel exploration of therapeutic strategies for MS, including complementary and alternative therapies. Welcome, Dr. Bourdette.

**Dennis Bourdette:** Thank you.

**Tracey Kimball:** We also have Dr. Robert Motl, who is Associate Professor of Kinesiology and Community Health and Director of the Exercise Neuroscience Lab at the University of Illinois at Urbana-Champaign. Dr. Motl is a published researcher in kinesiology and neuroscience, who examines the relationship between physical activity and relationship to improved quality of life, and Co-Founder of the Internet Physical Activity Intervention in MS Project. Thanks for being here, Dr. Motl.

**Robert Motl:** My pleasure.

**Tracey Kimball:** Additionally, we're joined by Dr. Nicholas LaRocca, who is Vice President of the Healthcare Delivery and Policy Research at National MS Society. Dr. LaRocca is a Clinical Psychologist and he manages the Society's Quality of Life and Symptom Management Research. Welcome Dr. LaRocca.

**Nicholas LaRocca:** Thank you, Tracey.

**Tracey Kimball:** I'd like to ask each of you how your work fits into the quality of life research we're discussing today. But for starters, Dr. LaRocca, what do you mean when we say quality of life? Isn't it different for everybody?

**Nicholas LaRocca:** Well, you hit on a very good point, Tracey, that quality of life does mean different things to different people, because it really means those things that are important to each individual. However, when you think about quality of life, there's certain things that really are universals, certain things that are important to just about everybody -- the ability to walk, freedom from pain, vision, having a safe place to live, having enough to eat, and so forth.

And a condition like multiple sclerosis tends to undermine what's known as health-related quality of life, and so those aspects of quality of life that are most related to the physical aspects of life. And when those physical aspects of life, such as walking and vision, are affected by MS, it tends to undermine the other aspects of quality of life, like employment and financial security.

**Tracey Kimball:** Dr. Bourdette, how do complementary therapies impact quality of life for those with MS?

**Dennis Bourdette:** Well, Tracey, I think we should start by defining what we mean by complementary medicine.

The term is commonly used as complementary and alternative medicine, or CAM, and these are comprised of a variety of therapies which have in common that conventional physicians don't prescribe them and there is very little or no research establishing their effectiveness.

Complementary therapy is something that a person is using in addition to what their physician is prescribing. So somebody that's on a disease-modifying therapy and follows a low fat diet for their MS is using diet as a complementary therapy. Somebody who's not on medications for spasticity but is using yoga or acupuncture to manage their spasticity is using that as an alternative to a medication.

Now, one thing we know is that a very high percentage of people with MS try CAM therapies -- up to 75%. And we also know that they're reporting that they're doing that in order to take better control of their health and to improve their symptoms and improve their quality of life.

And so the role of CAM is very important for us to understand because people with MS are experimenting on their own without much guidance from their physicians, often, and we need to be able to provide better information for them.

**Tracey Kimball:** Thank you. Dr. Motl, what type of research are you doing that affects people and quality of life of living with MS?

**Robert Motl:** Well, thank you again, Tracey. And I owe a great deal of gratitude to many collaborators and graduate students and also people with MS who have contributed to our research over the years.

And the research that we're doing is really -- it involves four arms. We try to study physical activity in MS. We want to know whether or not people with MS are

physically active or not. And if they are physically active, what types of physical activity are they doing? Are they walking? Are they jogging? Are they swimming? Are they gardening? Things like that, so that we can begin to help people with MS become more physically active.

The second thing we do, which really doesn't get a lot of attention or create a lot of enthusiasm, is the measurement of physical activity. But when you think about it, it's critical to really be able to precisely measure physical activity so we can prescribe the amount of physical activity that people need to do to improve their quality of life and reap many of the other benefits of physical activity.

The third line of research really becomes relevant to our session today, and that is we look at physical activity and how it's related to things like quality of life, mobility, and the management of symptoms. And based on that, we've started our fourth line of research, which really involves how do we get people with MS to be physically active? And how do we do that in a way that is broadly accessible to a great number of individuals who might not have access to exercise facilities and things along those lines?

So, we're really looking at the complete picture of physical activity and quality of life in MS.

**Tracey Kimball:** That sounds terrific. Dr. LaRocca, what kind of research is the Society funding to improve quality of life?

**Nicholas LaRocca:** Well, Tracey, I'm glad you asked me that question because I think that not everyone knows that the Society really has a holistic approach to MS research. And right now, the Society has over 325 new and ongoing research projects looking at various answers to that question.

And the Society's research philosophy can be summed up in that our goals are to stop the progression of MS, to restore function, and to end MS forever. And in order to pursue those goals, we fund a very wide variety of research, and I'll give you a few examples.

So, for example, at the present time the National MS Society is funding research looking at ways in which exercise can improve the strength of individuals who have been weakened by MS. In the past, the National MS Society, through its basic research and through its clinical research, has contributed significantly to the development of most of the disease-modifying drugs that are currently on the market.

In addition, the Society has funded research that has looked at depression and other emotional effects of MS, what the causes are and how they can be treated. We've also looked at cognitive dysfunction and how cognitive dysfunction can be treated. At the present time, we also are funding a study at UCLA, which is examining the potential effects of exercise to improve cognitive function.

We also will be funding a study that will be beginning very shortly that will be looking at the potential benefit of Vitamin D therapy as a way of altering the course of the disease. We also have been very interested in the different effects that MS seems to have in terms of men and women.

And the observation that during pregnancy multiple sclerosis exacerbations seems to decrease, and so there's a large clinical trial currently underway out of UCLA that is looking at the potential benefits of a combination of glatiramer acetate, which is one of the currently FDA approved drugs, in combination with Estriol, which is a sex hormone that tends to increase during pregnancy -- the effects of that combination on the disease activity in MS.

We've also funded research looking at caregivers of people with more severe types of MS and what their needs are and what their situation is. And we also now, during the next few years, have an important goal to promote research looking at the progressive forms of MS, which have really been relatively neglected in the past.

So, that just scratches the surface in terms of some of the types of studies that the Society has funded. And we're always looking for new ideas to help to maintain and improve quality of life for people with MS.

**Tracey Kimball:** Outstanding. That's wonderful news and very encouraging.

Continuing our look at the holistic approach to treating MS, an important area that deserves attention is complementary and alternative methods, as we've said is CAM. CAM includes a variety of things from exercise and dietary supplements to stress management strategies and acupuncture. Fortunately, a greater effort is being made to find ways to evaluate the safety and effectiveness of various types of CAM.

Dr. Bourdette, will you share with us why CAM has become an area of interest for you?

**Dennis Bourdette:** It was an accident. I had been studying for a number of years an animal model of multiple sclerosis. And I decided to look at a natural antioxidant

called lipoic acid, and we discovered that lipoic acid was highly effective at treating this animal model of multiple sclerosis.

Lipoic acid is a dietary supplement that you can go down to the health food store and buy, and we were intrigued by the idea that a relatively inexpensive antioxidant that was widely available might be effective in MS. We've gone on to actually begin studies in patients and, in fact, we're doing a trial of lipoic acid for optic neuritis that's funded by the National MS Society.

Along with that, I became intrigued about what people with MS were doing. So we did a survey of Oregonians with MS and found out that 75% of them were trying CAM, and they weren't discussing it by and large with their physicians.

The other thing we noted was that most people were trying things that were low cost and made a lot of common sense like eating a healthy diet, doing yoga, and weren't doing a lot of bizarre or dangerous things. They also were reporting that they often derived benefit from various CAM approaches, usually in the form of improvement of certain symptoms and improvement of their quality of life.

So I had, for a physician, kind of a novel thought -- maybe my ignoring CAM wasn't such a good idea. Maybe I should listen to what people with MS were saying, and so we began looking at things that they were reporting providing benefit. And it's always been very important to me, though, that we study CAM approaches in scientifically rigorous manners because that's the only way we'll determine what works and what doesn't.

**Tracey Kimball:** And that's an important point. And that being said, this ongoing research has taken place in CAM therapies for MS, are there particular challenges that researchers are having evaluating them?

**Dennis Bourdette:** One challenge has been overcome, and that is getting funding for the research. So the National MS Society, the National Institutes of Health, and the Department of Veterans Affairs all will fund appropriately designed studies of CAM therapies for MS and other diseases.

A lot of the CAM approaches can be studied the same way we study drugs. So if you're looking at a dietary supplement -- say, American ginseng extract or ginkgo or lipoic acid, you can do a placebo-controlled trial where people take either the active supplement or placebo. And there, we have a lot of knowledge of how to design trials for that type of approach.

But a lot of the CAM approaches you can't study that way and you can't blind patients from whether or not they're doing yoga. Or if you're doing a study of low fat diet, you can't blind them from that.

So, there you have to come up with creative designs and use objective outcome measures and have the evaluators -- that is, the physicians and researchers that are evaluating outcomes -- blinded to what patients are controlled to.

So there are challenges, but they're no different than the challenges of studying the effects of diet in helping to control diabetes. So we have funding and we know how to study these things; it's just a matter of deciding where to put one's effort and what's most worthy of studying.

**Tracey Kimball:** I see. That's very interesting. Can you tell us anything you've seen move from the complementary and alternative therapies world into the mainstream medicine world?

**Dennis Bourdette:** Not very many things thus far. The main obstacle is that conventional physicians want to have evidence that something works -- objective evidence. And so far, there's not been a wealth of research that's been done on CAM therapies for MS.

I'm part of a panel that is reviewing the world's literature on CAM in MS; identified over 1,000 articles, but only about 100 of them were scientifically sound and could be evaluated. So, we need more research.

I think that yoga is something that's been studied somewhat in MS and is starting to show some benefits and is becoming more accepted as a recommended exercise approach by conventional physicians. There's a lot of research outside of the MS field on the anti-inflammatory effects of Omega-3 fatty acids, and that's a supplement that I think more physicians are becoming comfortable recommending.

But a lot more research needs to be done before we're going to see CAM approaches move into the MD's office.

**Tracey Kimball:** Yes, and we hope that day comes soon, don't we?

Dr. Motl, you're engaged in research and how exercise may help people with MS, better manage their disease. Can you describe some of your approaches?

**Robert Motl:** We've taken two real approaches to understanding exercise and physical activity and how they relate to managing MS. And I think it's important that we differentiate exercise from physical activity. When we talk about exercise, we're talking about really planned, structured, repetitive things that are performed in like a gymnasium or a standardized environment -- things like jogging or lifting weights, things along those lines.

Whereas when we talked about physical activity, we're talking about something a little broader. We're talking about just bodily movement that results in energy expenditure, and this can be accumulated in a number of different ways. You could accumulate it through doing household chores like vacuuming or raking, mowing the yard, gardening.

You could accumulate it on your job as part of your occupation. You could accumulate it through transportation such as, if possible, parking your car a little bit further from the front door and walking a few extra steps, taking the stairs, if possible, as opposed to the elevator. And in leisure and things like that as well, so, taking a walk after dinner around the block, playing with your children.

So, physical activity is much broader and probably something that's easier for a lot of people with MS to do. So relative to exercise, we're really trying to understand what are the characteristics of exercise that matter for improving quality of life and managing the different symptoms? Should it be a combination of different types of exercise or should people engage in just one type of exercise? Does it have to be a certain intensity or not? Things along those lines.

With physical activity, what we're really trying to study is how do you promote lifestyle physical activity? How do you get people to adopt this and engage in it as part of their life? And that really, to us, involves teaching people the skills, the techniques, the tools to adopt this lifestyle and do it on a daily basis and to begin accumulating the many benefits.

So, we really are looking at exercise and physical activity as separate entities that perhaps could even be combined and have even greater benefits.

**Tracey Kimball:** You've been talking about benefits of exercise, and is it true to say then that most people with MS would benefit from doing exercise?

**Robert Motl:** I think without a doubt --.

**Tracey Kimball:** -- or physical activities? Sorry.

**Robert Motl:** Yes. No, no, it's good that we keep those at that broad level. I think everyone with MS could benefit from exercise and physical activity.

The standard benefits apply in people with MS. If you engage in regular exercise, you can improve your aerobic capacity; you can improve your muscle strength, your endurance; you can have a better body composition; you can improve flexibility, balance, motor skills.

But beyond that, I think some of the pertinent benefits are management of spasticity, management of fatigue, management of depression and pain, things along those lines. And also, increasing a perception of control over your disease and your life. And that's something that we shouldn't take lightly because individuals who have a greater perception of controllability over their life, over their disease, often times report better quality of life, and that's so important.

Perhaps one of the most exciting areas that we're starting to generate information on is the effects of exercise on cognition. And Dr. Bourdette and his colleagues have done some very early, promising research to kind of set the stage for a lot of what's being done at UCLA and now being done at University of Illinois to understand how physical activity, exercise, might help to improve cognitive function in people with MS and whether or not that really relates to changes in the underlying structure and function of the brain. And potentially, whether you can have a disease-modifying effect.

So, we're really entering into this exciting time where the standard benefits apply. But give us a few years and we might have really exciting news on even new benefits that no one ever expected.

**Tracey Kimball:** Good. That's really exciting and very encouraging for most people who are listening in who have MS, I'm sure.

We have some questions now from our web audience. Dr. Bourdette, Lori from Alabama would like to know if chiropractic care is useful in managing overall health in people and with MS.

**Dennis Bourdette:** So, back to my review that we were doing, there are no clinical trials of chiropractic therapy in multiple sclerosis. So we don't have any objective data to guide us. I think that chiropractic manipulation has been shown to be useful for acute low back pain, and I have a number of my patients with MS that have low back problems, often because they're walking is abnormal or because they have to spend a

lot of time in a wheelchair or motorized scooter and develop low back pain. And acute flare-ups of that sometimes can be helped with chiropractic manipulation.

I do caution people against having cervical chiropractic manipulation. I've seen a few patients that have had major exacerbations within the spinal cord in the neck shortly after having a chiropractic manipulation of their necks, so I think that's not a good idea.

And I think that if somebody's doing chiropractic manipulation for their general health and they feel better about that, I think that that's fine. You shouldn't be using that as an alternative approach where you're just using that to manage MS, but it should be part of comprehensive approach that would include appropriate use of disease-modifying therapies.

**Tracey Kimball:** Good to hear that. That's very good news.

Our audience is sending some questions in as well. Dr. Motl, Jackie writes, I was recently diagnosed with MS and am now somewhat fearful of overdoing it. What types of exercise do you recommend and how can she be sure that she's not working against her body or against her MS?

She says she was formally very active and she's now concerned that if she gets overheated in exercise or works out too hard she'll bring on an attack or fatigue herself. What are your thoughts and advice on that?

**Robert Motl:** I think Jackie shares a very legitimate concern that's shared by a lot of individuals with MS when thinking about engaging in exercise in the context of this disease. And I think it is a legitimate concern. That is, is that we don't want individuals with MS to go out and overdo it because we definitely can see some temporary symptoms exacerbation, we can see some worsening that's temporary, but then tends to dissipate.

One thing I would say is that at least in my review of literature, I don't see any evidence to suggest that a well-designed exercise program actually makes the disease worse, that is, would increase the rate of relapses or increase the rate at which the disease progresses.

So I think the important thing for people with MS to think about is that they should engage in all types of physical activity and exercise. They should consider engaging in aerobic exercise to build their endurance. They should consider engaging in muscle strengthening exercise to build their muscle strength and function.

You can even train balance. And I never knew that until I started doing some clinical trials to look at how you can manage balance and improve balance, and you really can do that. And you also need to focus on flexibility and stretching.

I think the simple rule is listen to your body. Your body has a natural way of telling you that you're doing too much. And it will tell you when to back off, and it will tell you when it's also ready to be able to do more. I think the other sage advice is to choose something enjoyable, something that you enjoy doing, and choose an environment in which you do it that's enjoyable; choose significant others that are enjoyable to engage in physical activity with.

And finally, talk with your neurologist and ask for their advice, see a physical therapist and ask for their advice, really, so you can get some good recommendations on where you might go and what you might do. But there really is a great opportunity to engage in exercise safely.

**Dennis Bourdette:** Maybe I could add something to that. I think one of the key things also is to control body temperature. So, a lot of the temporary worsening that people experience with MS when they exercise is partly due to --.

**Robert Motl:** Yes.

**Dennis Bourdette:** -- partly due to deconditioning, but it's also because it raises their body temperature and that can temporarily make symptoms worse. So, be mindful of keeping your body temperature down and doing exercises not in a hot environment but in a cool environment, and other approaches is really important for people with MS to tolerate it.

**Tracey Kimball:** Yes. Dr. Bourdette, Jo wants to know, from Alaska, why that would be? Is there a clinical answer as to why heat and humidity would affect her mobility?

**Dennis Bourdette:** That's actually pretty well understood. There's a lot about MS that we don't understand, but that is something we understand pretty well, and has to do with what happens when the nerve fibers lose their myelin sheath and get demyelinated.

Those nerve fibers become very sensitive to changes in body temperature. So they may be able to function normally at a normal body temperature, but even slight raises in body temperature, because you're in a hot room or outdoors in hot weather or

because of exercise or because of a fever, can make those demyelinated nerve fibers temporarily shut down until the body temperature is brought back under control.

So, it's all related to having nerve fibers that have lost their insulating material.

**Tracey Kimball:** Dr. LaRocca, Kathleen in Florida expresses concerns over cognitive challenges that are impacting her quality of life. She asks, I'm afraid to start talking because I'm not sure if the words will be there or if the right ones will come out. I start telling a story, she says, and forget what I'm talking about. How do I explain word searching and being disconnected in a conversation to friends and family?

**Nicholas LaRocca:** That's really an excellent question and is one of the most frequent complaints that we hear from people who have MS. And the technical term for it is problems with verbal fluency or word finding, but most people just refer to it as the tip-of-the-tongue phenomenon.

And it's something that we're all familiar with because we all experience it from time to time. And what many people without MS don't understand is that the experience the people with MS have is really qualitatively different; that it's much more severe, it's much more frequent. And so the reassurances the people with MS often get from the people around them who say, oh, that happens to me all the time, are not really that helpful because it reveals a lack of understanding of the problem.

And the underlying problems seem to be related to a couple of different things -- probably some memory issues and also probably some difficulty with the speed of information processing.

And there's a few things that people can do in order to try and deal with this. Number one is to try and help the people who are around you to understand what this problem is all about and that it really is something to do with MS. Number two, to maybe try to plan your thoughts ahead of time, sort of make up a script in your head so that when you do begin to talk you really have a pretty good idea of what you're going to say.

Also, once people around you, particularly your family, understands what the problem is, if you can just sort of gently explain to them that it's very difficult for you and others with MS to continue to say something that they're trying to explain if they are interrupted. And so it is best if the people around them can avoid interruptions.

And lastly, it's also possible to work with a professional, maybe a speech pathologist or an occupational therapist or neuropsychologist, just to learn ways to help the individual to perhaps speed up information processing, maybe improve memory a little bit.

**Tracey Kimball:** Thank you, Dr. LaRocca, that's very helpful. I'm taking your cue regarding planning ahead. What if, Dr. Bourdette, your neurologist will not discuss with you a CAM therapy if you're considering using one, if you have MS?

**Dennis Bourdette:** Well, that can be a problem. I think there's more openness now with neurologists, particularly with younger neurologists because of their own exposure to CAM approaches.

But if your neurologist doesn't have time for it or is not interested or -- more often than not, the problem is they're either very negative or they don't know anything, and it's better to admit you don't know anything than to say it doesn't work.

It is important to get good information, though. So, if you just go on the web and type in Chinese herbs in multiple sclerosis, you'll get a lot of information that is more misinformation than information. So it is difficult to find good information.

The National MS Society is a good source. They have information about a variety of CAM approaches. And I think you can also look for studies that have been done. People can Google search actual research studies that are published in qualified journals.

**Tracey Kimball:** All right.

**Dennis Bourdette:** So it can be a challenge, but there are good resources available.

**Tracey Kimball:** We should just go ahead and try ourselves. And if it is safe, we should go ahead and do that, right? Talk about it with a neurologist, but it's not really up to the neurologist to tell us whether it's appropriate for us, knowing our bodies the way we do with MS and our challenges. We should try it and see if it works for us. Would that be an approach you would encourage?

**Dennis Bourdette:** I think that it's -- you said at the opening that MS is highly variable and everyone's an individual, and I think that it is important for people with MS to take control of their health. I had one of my patients when I was being too direct tell me, "hold on, I'm the CEO of this body, you're just my advisor."

So I try to remember that, that each person with MS is the CEO of their health. I don't think -- as long as you're not doing something that's dangerous or is excessively expensive or is taking away from conventional medicine and what it has to offer, to experiment to see if a certain approach will make you feel better and helps control certain symptoms.

**Tracey Kimball:** Thank you. I like that.

Now, Dr. Motl, is there an approach of exercise that you could recommend for people -- or is being researched for people who have progressive MS or someone who has very limited to no mobility?

**Robert Motl:** It's a great question, Tracey. And almost everything we know about exercise and physical activity in MS is in individuals who are really in the relapsing-remitting phase of the disease or who have, for the most part, intact mobility.

We've started initiating three different lines of research to try to develop and work with developing alternative ways of engaging in exercise for persons with limited or no mobility. So, one of the things we're doing right now is this idea of body weight supported treadmill training, where you can put someone in a harness and safely put them on a treadmill and help them to move their legs through a normal walking cycle.

And the theory is this helps to retrain the central nervous system, the spinal generators and spinal pathways, to enable someone with MS who has a loss of mobility to begin to be able to walk again.

We're also looking at functional electrical stimulation cycling as a way of allowing people to have their muscles electrically activated while they're on a bicycle and allow them to engage in a normal aerobic exercise stimulus.

And one of the more interesting things that we're doing -- and this might sound a little bit peculiar and funny, but it holds a great deal of promise. We're doing what's called occlusion resistance training. That is, we're trying to identify a new way of developing strength in the leg muscles of individuals with MS.

And what this involves is the recognition that people who have a loss of mobility probably have a major loss of drive to their muscles and the capacity to activate their muscles. And so they can't undertake enough of a resistant stimulus or load to actually reap adaptations.

So what we're doing is we're adding an occlusion to the leg to limit blood supply to the muscle while someone is exercising. And what this does is it stimulates and creates an environment that mimics very intense and heavy exercise and results in much greater adaptations.

This has been demonstrated in people who don't have any mobility problems and it's been demonstrated in older adults. We've started doing it in chronic kidney disease patients and now we're doing it in people with MS, and it holds a lot of promise. So, I think there's a lot of things in the burner right now -- or are on the burner right now - - that will give us a lot more information in the very near future on new approaches to improve mobility and to reap these important quality of life outcomes in people with progressive MS.

**Dennis Bourdette:** The occlusion, that's not recommended for home use at this time.

**Robert Motl:** Well, yes. The technology is not quite there for home use. Dennis, that's a really good point. And I don't want anybody generating a tourniquet around their leg and --.

**Tracey Kimball:** I was going to ask you to explain that. I was going to ask could you explain to our audience and to me what an occlusion is?

**Robert Motl:** So, think of it as a very fancy blood pressure cuff that we're putting around the leg up by the groin area and we're inflating this to an appropriate pressure. And we're doing this in a laboratory under very controlled, precise conditions to reduce blood flow to the working muscle.

**Tracey Kimball:** Oh.

**Robert Motl:** And then have people engage in a very, very light amount of exercise. It's something that if you didn't have any limitations or disability you would actually think isn't any exercise at all. And it really has shown great benefits in a variety of other populations, but clearly, not something that people should start doing on their own in their home. I'm glad you pointed that out, Dennis.

**Tracey Kimball:** Got it. Thank you.

**Robert Motl:** All of these things are very experimental that I just talked about.

**Tracey Kimball:** We won't be doing that at home. Right, audience? Dr. LaRocca. Could you tell me if the disease-modifying -- we're talking a lot about CAM therapies, which is very exciting in today's world; however, a lot of us are on disease-modifying therapies. Do you know, can you tell us, are those effective? Do they change the quality of life for people with MS, by and large?

**Nicholas LaRocca:** Well, the short answer is yes. And there are two lines of evidence for that. Number one, that, as we know, the disease-modifying therapies have effects on disease activity in MS. So, in other words, they reduce exacerbations. They can slow progression. They can even, in certain instances, prevent for a period of time the onset of actual MS.

And so by preventing some of the physical effects or limiting some of the physical effects of MS, they therefore contribute to maintaining and improving quality of life because it's those effects of MS, to some extent, that undermine quality of life.

And the second line of evidence is the fact that in many of the clinical trials of these therapies, that the investigators have included measurements, assessment techniques, that look at quality of life, that ask the people in the studies about their quality of life. They compare the treated groups with the placebo groups or the two comparison groups.

And interestingly enough in the last few years the FDA has become very interested in this whole issue of do therapies improve quality of life? So at this stage, it's no longer good enough to simply show that a therapy can reduce exacerbations or slow progression; that it's important to also show that it has some effects that would be recognizable and would be important to the patient, i.e., quality of life.

And so in the future we're going to have mounting evidence as to whether or not therapies that are under development have an impact on quality of life.

**Tracey Kimball:** Excellent. I'm going to move onto the subject of fatigue, which is a very, very common symptom in many of us MS people. It can be very debilitating. And I'd like to know from each of your perspectives what can be done about it? Is there research going on about fatigue specifically in MS?

**Nicholas LaRocca:** I guess I can start off. There's a great deal of interest in fatigue, and maybe we should start off by just talking a little bit about what fatigue means in MS and my colleagues can add to that, of course, if they wish.

And so in MS, you have the type of fatigue that refers to what happens to muscles that are expending effort in a person with multiple sclerosis. And it has been observed for quite a long time that when you repetitively use a muscle, if you have MS, that that muscle is going to get tired, so to speak, sooner than it would in someone without MS. And so that's fatiguing of the muscle itself.

But then there is the other type of fatigue, the sort of lassitude or exhaustion that people with MS experience almost universally, which tends to have its own daily cycle, usually in the late afternoon and, to some extent, doesn't really matter what you've been doing or haven't been doing. When that time arrives, so does the fatigue.

And there are a number of strategies that people are looking at in terms of combating fatigue, including research on time and energy management, trying to plan your day or plan your activities in a way that will conserve your energy, as well as pharmacologic approaches that may perhaps stimulate energy a little bit more in people who are suffering from fatigue.

Well, let me stop there and turn it over to my colleagues, who can elaborate on some other strategies as well.

**Robert Motl:** So, one of the things that I think is almost conventional wisdom nowadays is that when individuals with MS become deconditioned over time, that is, they become detrained, is another way of saying it, that every activity that they do becomes a little bit more difficult for them and that ultimately leads to more and more fatigue.

And so if you take that approach, then one of the things you can do is engage in exercise and build up your different fitness capacities, your endurance, your muscle strength, things like that, to make those everyday activities less demanding for an individual and less fatiguing over time.

Now, at first, there might be a little price to pay for that because obviously being physically active involves expending some of your resources of energy. And so it's kind of like you have to make a little bit of an investment in spending a little bit of your energy pool to get your body in better condition to be able to handle the daily stressors, demands that zap your energy.

So, I think exercise, there's a great deal of evidence -- and Dennis, you guys have generated a lot of that evidence, for aerobic exercise and yoga as a way of managing fatigue.

**Dennis Bourdette:** And I think besides the improvement in muscle strength, exercise helps the generalized fatigue or lassitude or exhaustion that Nick was talking about. I think that's probably the number one thing right now that we have to help this generalized fatigue.

There are medications that are used for the generalized fatigue that are what we call off-label; that is, they're not FDA approved for treating MS-related fatigue, but there have been some clinical trials to show that there's some benefit. I think those medicines work very well in maybe a third of the patients and not so well in the remainders. And I think the foundation for fatigue management has to do with energy conservation and an exercise program.

There is a third type of fatigue that we should mention that's referred to as nerve fiber fatigue. So that's, again, related to those demyelinated axons. Not only are they sensitive to heat, but they use up their energy. And so this is a phenomenon of, well, I can walk a block fine, but after I walk a block I start dragging my left leg and I have to stop and rest. So this nerve fiber fatigability is quite different than the other two types of fatigue we've talked about.

And there is now a medication that is FDA approved for improving walking speed, but what it's doing is it's making these demyelinated nerves work better. That's a medicine called dalfampridine. It works very well in maybe 30% to 40% of MS patients, but it is the first FDA approved drug that can actually make these nerve fibers function better.

**Tracey Kimball:** I have heard of that. Something that also can be very fatiguing, I have found, is stress. When I go through stress in my life, specific stressful episodes, I get much more fatigued, and I think that's a common symptom amongst many people with MS. Dr. LaRocca, what do you think can be done about that?

**Nicholas LaRocca:** Stress is a topic that has been of great interest in MS for quite a long time and for many reasons. And many people have attributed different roles to stress. Many people have thought that stress can trigger MS or can make MS worse. And the scientific evidence for that tends to be very controversial at this point and inconclusive.

And many people with MS have been told to try and avoid stress -- either to prevent stress from making their MS worse or to avoid stress causing fatigue. And while it's a nice trick if you in your life can avoid stress, most people find it hard to completely avoid stress. And I think that there are three things that you can do in order to approach stress if you have MS, or if you don't have MS.

Number one, going back to the idea of avoiding stress, you can't avoid all stress. But I think if everyone examines their life, there probably are certain sources of stress in your life that are unnecessary. So, if you can find sources of stress in your life that you can escape from, that you can eliminate, it would not be a bad idea to do so. There's no reason to put yourself under more stress than is absolutely necessary.

Number two, it's, to some extent, not the stress itself but the way in which we appraise or evaluate the stress that seems to have an effect on us. And so it is possible to learn different ways to evaluate or appraise stress so that it does not have the same negative impact on us.

And lastly, there are a number of physical things that we can do to deal with the physical aspects of stress, and we've talked about some of those -- exercise, yoga, relaxation, visualization, medication, and so forth. So there's a lot of things that you can do about stress that can be very helpful.

**Dennis Bourdette:** Tracey?

**Tracey Kimball:** Yes.

**Dennis Bourdette:** This is one of those areas where there's a big disconnect between neurologists and people with MS. So, if I go into an audience where there are people with MS, say 100 of them, I ask, how many of you think stress affects your MS adversely? Almost every hand goes up in the audience.

A hundred neurologists, you ask, how many of you think stress affects MS? And there will be one hand up, and it would probably be mine. So, I think Dr. LaRocca has aptly summarized this difficult literature as conflicting on the role of stress.

But it's pretty clear. Most people with MS, while it may not be making their MS permanently worse, it commonly makes symptoms worse. And I think the advice that Dr. LaRocca has given us is excellent in terms of practical things that people can do.

**Tracey Kimball:** Terrific. I think that's a wonderful approach. It's how we interpret things a lot of the time, isn't it? Dr. Bourdette, while I have your attention, Mike in Arizona asks if you would discuss, please, the value of diet modification as a complementary therapy for MS.

**Dennis Bourdette:** So, there's a decade's long history of diet as a therapy for MS.

**Tracey Kimball:** All right. The shorter answer then possibly, please. Short details.

**Dennis Bourdette:** You don't want that 40-year history? There's been a longstanding interest in a low fat diet as a treatment for MS, and the biggest advocate for that was a neurologist by the name of Roy Swank, who passed on a few years ago.

We think that there's reason to believe that a low fat diet has some benefits in terms of being an anti-inflammatory, having effects on the immune system, and perhaps a neuro-protective role. But it's just never been studied in a rigorous manner.

We're actually doing a trial now of a vegan diet, which is quite low in fat, looking at brain atrophy as an outcome measure. So patients have been randomized either to go on this very low fat vegan diet or to continue on their standard diet, and are trying to gather some data to actually look at whether it's beneficial. But right now, we don't have good data to support using diet as a treatment for controlling the disease.

But I think there's plenty of reasons to believe that if you're not overweight eating a healthy diet, exercising and getting your weight normalized is going to have definite long-term benefits in terms of adapting to MS.

**Tracey Kimball:** On the subject of healthy diet, Jill and Ellen in New York wanted to know if Vitamin D supplements are important in MS and what the ideal blood level of Vitamin D would be.

**Dennis Bourdette:** Is that for me?

**Tracey Kimball:** Yes.

**Dennis Bourdette:** The Vitamin D story in MS is fascinating. There's two very good studies that establish that a low Vitamin D level increases your risk of developing MS. And there's now some data to suggest that a low Vitamin D level if you have MS can actually increase the likelihood of having a relapse, and the National MS Society is funding a trial to look at that very question.

And if you measure Vitamin D levels, particularly where I'm from in Oregon, three-quarters or more of the patients have abnormally low levels. So I think it's important for people with MS to have their blood level checked. Normal range is 30 nanograms per mil to 80 nanograms per mil.

And if it's low, I think it makes common sense to take a Vitamin D supplement to normalize the blood level. And we usually aim for a level in the 40 to 60 range. And

there's no evidence, however, that taking prolonged high doses of it will drive the level above a normal range is beneficial and may be harmful.

**Tracey Kimball:** Okay. So, in lay terms, how much would I take on a daily basis to achieve that?

**Dennis Bourdette:** Typically, in Oregon, it runs 2,000 international units to 5,000 international units a day --.

**Tracey Kimball:** A day.

**Dennis Bourdette:** -- to be able to get it into and keep it in a normal range.

**Tracey Kimball:** Good information. Good advice. Dr. LaRocca, this is from Sarah in Louisiana. She asks, how does one involve close family members and friends in the day-to-day struggle of living with MS without becoming a burden or making them feel uncomfortable with the subject? She says her biggest fear is making those around her feel uncomfortable, but her greatest relief is talking about MS.

**Nicholas LaRocca:** A very common dilemma, and I guess I would leave you with one phrase that was coined a few years ago that we like to call the democracy of coping, which kind of sums up the fact that no two people cope with MS in the same way.

And whether it's a married couple or family, what we have found in working with people who have MS is that people have very different approaches to dealing with it. Some people when they're diagnosed, they want to read everything they can get their hands on. They want to talk to everybody about it. They want to think about it. They want to really immerse themselves in MS.

Other people, maybe sometimes in the same family, want to just know the basics. They want to just know what's necessary and they don't want to think about it too much. They want to kind of push it off into a corner and go on with their lives. And that tends to create a tension within the family because the people are pulling in different directions. And I think the starting point in dealing with that is just to understand and to respect the differences, of the fact that people do have different ways of dealing with it.

And when you start to talk about MS with someone who is maybe not quite as open, if you begin to get that sort of deer-in-the-headlights look or the person looks

distracted, then it's kind of a signal that maybe you should back off a little bit, wait a little while, coming back at a later time or later day, reopen the subject.

And it's a little bit like talking about the birds and the bees with your kids. Only give them the information they need at the moment, and then supplement it as they're able to absorb and process the information that you've given them and then you can add more, and people will evolve and they will change over time.

So I think that that's the approach that can be very workable for people, but it really requires a tolerance and it may require that the individual who wants that immersive experience may have to find a friend or a support group or some other place where they can go where there are other people who really want to delve into MS and talk about it a lot.

**Tracey Kimball:** So, I guess what you're saying is be sensitive to other people's boundaries. When we might be feeling as MS people, we might be feeling a burden to share, the people in our family may not feel quite so burdened. An as needed basis? And information of as needed -- a need-to-know basis?

**Nicholas LaRocca:** A need-to-know basis. And I think the other important point is that an individual in the family may be very involved and very supportive even though they might not be talking that much about the MS or about their feelings. But they may really be there with you and really involved and really caring even though it may be a little bit hard to tell because they're not saying very much.

**Tracey Kimball:** The sensitivity there is key, too. Dr. Bourdette, someone who has a need to know about this specific thing is David in New York. He says he struggles with a burning sensation that's very painful in his extremities. I felt that myself, too. What can he -- what can we -- do about that when that happens?

**Dennis Bourdette:** Burning pain in MS, and typically it occurs in the legs, can be a very, very troublesome problem. It's caused by damage to nerve fibers in the spinal cord caused by the MS, so it's a symptom, a consequence of the MS. We use the term neuropathic pain to describe that type of pain. You can see that not only in MS, but in diabetic neuropathy and a variety of other conditions.

It can often be helped with medications. Again, some of this is off-label use; some of them are approved to treat neuropathic pain. And there are two broad classes of medications -- anti-seizure medications and anti-depressants. Now, it's not because the burning pain is caused by depression or caused by seizures, but it's because those medications affect the chemicals that are involved in mediating this burning pain.

Most neurologists are very familiar with treating neuropathic pain with medications, and this is definitely an area where one size doesn't fit all and you have to go through a process of trial and error. Some people, they can manage that burning pain most of the time, but it builds up at certain times like when they're quiet and trying to go to sleep or if they've overdone it.

And in most circumstances, sometimes a light sedative can be the best approach as opposed to taking a medicine several times a day like you typically often have to with these other classes of medications. And occasionally, some patients need to go to a pain clinic after they've tried several different things and if it's very incapacitating and affecting their quality of life.

**Tracey Kimball:** Is one of the CAM therapies for pain acupuncture? Has that been looked at by you or your clinic?

**Dennis Bourdette:** Acupuncture, in terms of treating MS, very few research studies have been published on that. Acupuncture as a way to help manage pain in a variety of conditions has been studied, and that is one of the examples of a CAM approach that's become more mainstreamed and many insurance carriers will cover acupuncture for painful conditions. So, sometimes acupuncture is useful for helping to manage pain in MS. But again, it doesn't work in everybody.

**Tracey Kimball:** I see. That's right, it is personal. Each of us has an individual body that needs to be individually taken care of that way.

Dr. LaRocca, from Margo in North Carolina. She says, please discuss mental fog. Is it permanent? What can she do to avoid it, delay it, or address it if she has it? I can relate, Margo. I'd like to know the answer, too, please.

**Nicholas LaRocca:** Sure. Mental fog is actually a term that has risen relatively recently. It's obviously not a technical term, and it really refers to a number of different effects of cognitive changes that may occur in MS related to memory loss, difficulties with concentration, problems with processing -- the speed of processing information.

And it's sort of that generalized feeling that you're not quite there, that you're not really able to function very well. And whether or not it's permanent, it seems to vary to some extent with conditions -- of our mental conditions and how tired and fatigued an individual may be.

And it also refers at times more specifically to what's known as cognitive fatigue. And cognitive fatigue is actually a scientific term -- again, something that has really risen during the last few years -- and is a particular type of fatigue that occurs when an individual, say, with MS, who has some cognitive issues, has been doing some very challenging intellectual task like accounting or analysis or something like that -- has been doing that type of work for an extended period of time and just feels mentally like they can't -- they're not as sharp, they really can't go on.

So it's a very particular type of fatigue which will pass once they are rested and they feel more able to resume their work, possibly the next day. The thing about cognitive changes, usually when they begin, they don't just go away, although in some cases they may. They can progress, like other symptoms, although the progression is often fairly slow. And also, like other symptoms of MS, they can get worse during an exacerbation and then improve when there is a remission. So, to some extent they behave very similarly to other MS symptoms.

**Robert Motl:** Tracey, may I make a comment on this?

**Tracey Kimball:** Yes, please.

**Robert Motl:** Now, I'm not trying to say that aging and MS are the same, but they share some things in common. And the reason I bring that up is because in the gerontology world probably one of the most exciting findings right now is the evidence that exercise training can not only slow cognitive decline with normal aging, but actually reverse and improve cognitive function in older adults.

And we're just starting to address that in folks with MS. But really, this is one of the most exciting things that is on the forefront is trying to understand how exercise might play a role in improving the cognitive function of individuals with MS, and it really is an exciting area of research that I think will come out in the next five years.

**Nicholas LaRocca:** Well, and the exciting thing, I think, about exercise is that if it didn't improve cognition, has so many other benefits for people with MS and for people in general. It's almost as if there's no downside to it unless you do it wrong and fall on your head or something like that.

**Robert Motl:** And we want to avoid that.

**Nicholas LaRocca:** We want to avoid that.

Tracey Kimball: That is very exciting and extremely encouraging that that research is undergoing right now. Dr. Bourdette, I've had a few questions that lead me to ask my next question. What do you think about treating MS only with alternative therapies? We've been talking about various forms of treating MS. What would you say to that question?

**Dennis Bourdette:** I think for somebody with relapsing MS, that's a bad idea. I think that the disease-modifying therapies that we have clearly are effective at controlling the relapsing phase of MS. So I think that patients with relapsing MS should be on a disease-modifying therapy and can use alternative therapies in addition to that.

Now, for people with progressive MS where none of the FDA approved therapies for relapsing MS have been shown to have much of an effect, I think there's a stronger argument to be made to, I don't want to be injecting myself or taking medicines that alter my immune system. I want to try an alternative approach.

I think also, when we talk about symptomatic therapies, which are not controlling the disease process but help people control symptoms, they can find alternatives to things that I might use my prescription pad for that could work for them; I'm all for that. But I think relapsing patients should not just be using alternative medicine; I think that's a mistake.

**Tracey Kimball:** Thank you. I appreciate that. Before we wrap up, I'd like to ask each of you what most excites you about the research you see on the horizon. We've talked about very encouraging research that's happening or is about to happen that could lead to breakthroughs to improving quality of life for people with MS. Dr. Bourdette, would you like to start?

**Dennis Bourdette:** The number one thing that would improve the quality of life for people with MS is to have a cure. While I don't see a cure on the immediate horizon, I do think that with early treatment, shortly after diagnosis in relapsing MS, that we're getting very good at controlling that form of the disease, and that has positive effects on the quality of life. So I'm very optimistic that over the next five years we'll have a palette of treatments that are highly effective at controlling relapsing MS.

Also, I think that over the next five to ten years we're going to see advances in our ability to treat progressive MS and in reparative therapies. So, I'm excited about our ability to do a great job of treating relapsing MS and evolving therapies that are effective for people with progressive MS.

**Tracey Kimball:** Yes, I'm excited with you. That sounds very amazing. Dr. Motl, what are you excited about?

**Robert Motl:** So, the one thing, I think, that gets me out of bed every day and makes me really excited is the possibility that exercise might actually have some neuro-protective effects. And what that means is that exercise might slow down the rate of formation of new lesions, it might help to improve the myelination in the white matter in the brain, and it might even help to maintain the gray matter and slow down atrophy of the tissue in the central nervous system over time.

We've seen this in normal aging and in diseases of the aging physiology and the aging system, and we're starting to do this research in folks with MS. And it really is a very exciting time to suggest that exercise might actually do something to the central nervous system and the tissue within the central nervous system.

And that really is something that gets me out of bed every day.

**Tracey Kimball:** And these are ongoing? You have mentioned before that these are ongoing researches --.

**Robert Motl:** Yes.

**Tracey Kimball:** -- that is happening right now as we speak. So, imminent change. Wonderful. We like that.

**Robert Motl:** We published some of the data, but the really important, larger studies that involve exercise training and really nicely controlled trials are underway right now.

**Tracey Kimball:** Terrific. I couldn't be more excited about that. I know I share that with most people in the audience who are looking for change. Dr. LaRocca, what are your thoughts on what is most exciting for you right now?

**Nicholas LaRocca:** I think what's most exciting for me is seeing the new people who are entering the field of MS research. And that includes the young researchers who are in their post-doc or exiting their post-doc training as well as senior researchers who had never done MS research before but that somehow we've been able to lure into doing MS research.

And earlier I mentioned our three goals of stopping the progression of MS, restoring function, and ending MS forever. And what we see are these young researchers and those researchers from other fields going into each of those target areas. And so I

think in the next few years we're going to see tremendous progress in all those areas, both from the new talent that's coming in and, of course, from the really excellent talent that we already have in the field.

So, I'm really very excited about what we can look forward to.

**Tracey Kimball:** Outstanding. Well, that's all the time we have for questions today. We did receive a few questions today related to chronic cerebrospinal venous insufficiency, or CCSVI. We want to let you know that the Society will be releasing in July its six-month update on the research underway at the seven grant sites.

I'd like to thank our panelists for your time today and for the important work that you do. I'd also like to thank all of you for participating and submitting your questions. We hope that you've found the program informative and timely. Today's webcast will be archived and available for viewing at [www.nationalmssociety.org](http://www.nationalmssociety.org)

If your question wasn't covered today or if you have additional questions about MS on the topics addressed by our speakers, please visit the National MS Society's website, [nationalmssociety.org](http://nationalmssociety.org), or contact one of our MS navigators in our information resource center for help at 1-800-344-4867. For additional webcasts that you can view on-demand, please visit the Society's MS Learn Online programs located in our multi-media library at [nationalmssociety.org](http://nationalmssociety.org).