

# Complementary Therapies and NMOSD

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**Intro:** [00:00:00] ABCs of NMOSD is a 10-part education Podcast Series to share knowledge about neuromyelitis optica spectrum disorder, or NMOSD, a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. ABCs of NMOSD Podcast Series is hosted by SRNA, the Siegel Rare Neuroimmune Association and in collaboration with the Sumaira Foundation for NMO, the Connor B. Judge Foundation and Guthy Jackson Charitable Foundation. This education series is made possible through a patient education grant from Viela Bio.

**GG deFiebre:** [00:01:00] Hello everyone and welcome to the ABCs of NMOSD podcast series today's podcast is entitled Complementary Therapies and NMOSD. ABCs of NMOSD is a 10-part education podcast series to share knowledge about neuromyelitis optica spectrum disorder. My name is GG deFiebre from the Siegel Rare Neuroimmune Association, and I will be co-moderating this podcast with Chelsey Judge. Chelsey, do you want to introduce yourself?

**Chelsey Judge, PhD:** [00:01:27] Hi. Sure. Thank you, GG. Hi, I'm Chelsey. I'm a PhD immunologist, sister to Connor - an NMO patient - and also scientific advisor with the Connor B. Judge Foundation. And then separate from my role, I'm also a medical science liaison with Sanofi-Genzyme, an MS in neurology, and I'm really excited to co-host this podcast episode today with GG.

**GG deFiebre:** [00:01:47] Great. Thanks so much. And this podcast series is hosted by the Siegel Rare Neuroimmune Association, in collaboration with the Sumaira Foundation for NMO, the Connor B. Judge Foundation, and the Guthy Jackson Charitable Foundation.

[00:02:00] This podcast is being recorded and will be made available on the SRNA website and for download via iTunes. This podcast series, the ABCs of NMOSD, is made possible through a patient education grant from Viela Bio.

[00:02:14] Viela Bio is dedicated to the development and commercialization of novel life-changing medicines for patients with a wide range of autoimmune and severe inflammatory diseases. Their approach to drug discovery is aimed at providing targeted treatments for improved outcomes for the thousands of patients who have few or no therapeutic options. For additional information about Viela, please visit [vielabio.com](http://vielabio.com). For today's podcast, we are pleased to be joined by Dr. Kyle Blackburn, Dr. Cindy Wang, and Dr. Ruchika Prakash. Dr. Blackburn is an assistant professor in the Department of Neurology at UT Southwestern Medical Center in Dallas, Texas. He received his medical degree from the University of Kentucky College of Medicine and completed his neurology residency at UT Southwestern. He then completed a fellowship in neuroimmunology at UT Southwestern, where he received training from Dr. Ben Greenberg. During his fellowship, Dr. Blackburn was a James T. Lubin Fellow, and he launched the Comprehensive Outcome Registry Exploring Transverse Myelitis, or CORE TM study a registry collecting patient reported outcome measures on adult and pediatric patients with transverse myelitis and acute flaccid myelitis.

[00:03:23] Dr. Cynthia Wang received her medical degree from the University of Texas Southwestern Medical Center in Dallas, Texas, and completed a pediatrics and pediatric neurology residency at Mott Children's Hospital, University of Michigan Health System in Ann Arbor, Michigan. Dr. Wang was also a James T. Lubin Fellow under the mentorship of Dr. Benjamin Greenburg. She's now an assistant professor in the Departments of Pediatrics and Neurology and Neurotherapeutics at UT Southwestern. Her primary area of interest is immune-mediated brain disorders, including ADEM and autoimmune encephalitis. And then Chelsea, if you would like to introduce Dr. Prakash.

**Chelsey Judge, PhD:** [00:04:02] Yes, of course. Dr. Ruchika Rashika Prakash is an associate professor in the Department of Psychology at the Ohio State University. She's a licensed clinical psychologist who's been doing research on lifestyle interventions and people with MS for the past 15 years. She's the director of the Clinical Neuroscience Lab, where she works with PhD students, undergraduate students, and postdoctoral associates all to better understand how physical activity training and mindfulness meditation can help improve cognition, reduce depression and anxiety, and impact brain plasticity in individuals with MS. She's published over 75 peer-reviewed journal articles, and her research is funded by the National MS Society as well as the National Institutes of Health. She's also a member of the Psychosocial Wellness Group at the National MS Society and frequently presents her research on topics of psychosocial wellness to various public audiences. She received the "Rising Star Designation" given by the Association for Psychological Science in 2013 and the Springer Early Career Achievement in Research on Adult Development and Aging by the American Psychological Association in 2016.

[00:05:05] Thank you so much for everyone for joining with us today.

**GG deFiebre:** [00:05:09] Thank you. So to start I guess if, if I could have each of you, please just briefly explain what complementary therapy means, you know, broadly, and then in regard to NMOSD. I'll start with Dr. Wang.

**Cynthia Wang, MD:** [00:05:24] Thanks. And thank you everybody for having us. Thank you to the SRNA. I think this podcast series has been so informative. I've listened through a few, and I think it's great to kind of further the conversation on how to manage this condition. So yeah, I would say complementary therapy are things that are perhaps like less well studied or less evidence-based, but can be, you know similarly effective depending on the person or their symptoms. In respect to NMOSD, I would say that would be things outside of the traditional or now, you know, FDA-approved drugs that we have, all three approved last year, which is really monumental for NMOSD, and some of the older drugs that we used to prevent relapses. And I think probably most of these types of therapies are along the lines of, you know, improving wellness and health and decreasing pain, improving quality of life. And I think many of the questions we'll cover relate to, to those aspects, including diet, role of supplements, different forms of therapy.

[00:06:24] So I'll pause there. I know some of the other guests probably have things to add.

**GG deFiebre:** [00:06:30] Yeah. Dr. Prakash?

**Ruchika Prakash, PhD:** [00:06:32] So, so for me, complementary therapies really, so, are what is defined by the National Center for Complementary and Integrative Health, which is that when we think about medicine and when we think about Western medicine, we often tend to think about pharmacological interventions. So complementary interventions are those that are used in addition to Western medicine and really approach the person as an integrative whole that, such that we're not really focusing just on trying to reduce the symptoms that they're experiencing, but are also focusing on developing the overall health and improving the quality of life of the person.

[00:07:12] So we're addressing cognitive issues that people may be experiencing. We're talking about issues of depression and anxiety. We're talking about pain from a more holistic perspective. But also working, going beyond the individual and developing social relationships and developing community that allows the person to grow as a whole.

[00:07:32] So that's what I would think as complementary therapies.

**GG deFiebre:** [00:07:36] Great. Thank you. And then Dr. Blackburn, do you have anything to add?

**Kyle Blackburn, MD:** [00:07:40] Those are both pretty great definition. So it's hard to elaborate too much. I think that's just been emphasized. We typically view the complementary treatments as those that are outside of that traditional pharmacological Western medicine approach. It doesn't mean that they are the, the only approach, it just means that they are in complement and trying to work hand in hand. Specific to NMOSD, as Dr. Prakash highlighted, those can be a whole wealth of different measures that can help enhance an individual's quality of life.

**Chelsey Judge, PhD:** [00:08:15] I like it. I think those are all really great responses. And I definitely appreciate that, and I think the NMO community will as well, that these are integrative and additive approaches. And so just kind of diving right into that then, some of these complementary approaches that are used: acupuncture and massage. Have these been used in NMOSD patients, and if so, which I know people are using, but is there any research that indicates that these methods are in fact useful? Dr. Prakash. Do you have any insight on this?

**Ruchika Prakash, PhD:** [00:08:45] So I have to say, I am not an expert in NMOSD, but I have done work with individuals with multiple sclerosis, and much of my work has focused on mindfulness meditation. But what I have read about massage and acupuncture, I actually haven't read much about it, but massage, it seems like it could be helpful for chronic pain.

[00:09:08] However, when you think about randomized control trials, and when you look at the efficacy data of massage for chronic pain, the effect seems to be pretty weak. So that's all that I have read about this literature, but I'll defer to Dr. Blackburn and Dr. Wang on this.

**Chelsey Judge, PhD:** [00:09:26] Thank you. Dr. Blackburn or Dr. Wang, do you have any maybe anecdotal experience of some NMO patients using either acupuncture or massage in some way to help?

**Cynthia Wang, MD:** [00:09:38] I can start on the, yeah. Yeah, I think, you know, a recurrent theme in many of our answers to these questions, it's, it has to be an individualized. And sometimes the best way for a person to know if it helps is just to try it and, you know, give it a good, you know, consistent try for a certain amount of time where you, you really give that therapy a chance.

[00:09:57] So certainly I've had people who've tried acupuncture, or you know, I recommend gentle massage. I think chiropractic manipulation is something that could have potential harm to the patient. I've certainly seen patients who've developed strokes and other things from forceful manipulation. But gentle massage, cranial sacral massage, I think myofascial release, things like this definitely can help certain individuals, because everybody's disease is different and may have affected different parts of your spinal cord. Your symptoms of weakness or pain may be different from the other, the next person. I think a lot of the, my, a lot of the time, my answer is, you know, it's definitely worth trying.

[00:10:36] It probably is not harmful. I think it's more of a, kind of an opportunity cost. Like, is it worth the time and potentially the financial investment that you would need to make in the therapy, and are you willing to

do that? Because unfortunately, I think one of the, the negative aspects is that because there's not as much rigorous scientific study of these treatments, many of them are not covered by insurance.

**Chelsey Judge, PhD:** [00:10:59] I think that's a really good point. It could be really costly to patients. Dr. Blackburn, do you have anything to add to that?

**Kyle Blackburn, MD:** [00:11:07] No. I absolutely agree. I think when it comes to things like acupuncture, the, the overall scientific rigor just hasn't been applied. So we do have to consider its potential benefits against its harms in the individual person. And in general, I've, I've taken a personal approach, of this, with acupuncture in particular, that this is not a therapy that has a high risk of harm, so it is reasonable to explore for at least a limited trial to see if, if the person notices any clear benefits. I agree ultimately, we do probably need to get better, more rigorous study of measures like this so that insurers might be willing to cover them if we do find a benefit.

[00:11:53] But, but ultimately that's, we're not quite there yet. In terms of massage. I do think that, I have had a number of patients go to them, get massage and say that they get some temporary relief. And certainly as Dr. Wang was talking about things like myofascial release is another technique that I've had patients use and anecdotally report benefit.

[00:12:12] So I do think that on an individual level, if these are things you're curious about and have access to them, it's reasonable to pursue.

**Chelsey Judge, PhD:** [00:12:19] Thank you so much, all of you, for that. And Dr. Wang brought up chiropractic technique and the potential harm it could cause to patients. Do either of you, Dr. Wang, Dr. Blackburn, discuss chiropractic, a chiropractor with your NMO patients, and if so, what purpose would a chiropractor serve for someone with NMO?

**Kyle Blackburn, MD:** [00:12:42] I don't mind jumping in. So in general I, I kind of find the way that I hear about chiropractic maneuvers is through patients coming to me having already gone through it, or just asking, inquiring about it. And certainly Dr. Wang brings up a valid concern that every neurologist is going to express, that especially aggressive manipulation of the neck, there's a risk of damage to arteries that run in the neck that feed the brain. So everyone gets very concerned about the risk of stroke. And I think every neurologist has had that patient in the hospital where they had a maneuver and subsequently had strokes.

[00:13:20] So, so we're always going to be very, very guarded, naturally, whenever it comes to neck manipulation. For lower extremity manipulation I'm a little more open to hearing about that. If somebody has a fair bit of back pain, I think that there could potentially be a role. I always want to make sure that they're going with someone Who has a pretty good reputation.

[00:13:42] I always encourage them to look into look into the person a little bit more because certain, certain people have been doing this for a long time. Making sure you're going with an experienced practitioner is always a great thing. But yeah, whenever it comes to things like lower back pain sciatica, there may be somewhat of a role there, but I certainly like Dr.

[00:14:02] Wang and very, very cautious around the neck.

**Chelsey Judge, PhD:** [00:14:05] Thank you. I appreciate that. Dr. Wang, do you have anything else to add, or do you feel all your points were addressed?

**Cynthia Wang, MD:** [00:14:10] No, I think that was definitely a perfect answer. I think, you know, again, just kind of going back to the kind of, you know, the calculus of this is you, you want to like maximize all the gain you can get from things that are known to be well-, you know, well-studied, well-proven and oftentimes, thankfully insurance covers some of those therapies.

[00:14:29] So if a person has an explored, you know, maybe a physical therapist who can do a lot of the same types of like manual techniques, stretching, exercise regimens, I would definitely try to, you know, like fill, fill your, you know, your, your wealth of information and care from those proven, or at least more proven aspects of our healthcare system.

[00:14:51] And then if that's just lacking, you're not getting the, the response or the improvement that you're hoping for, maybe at that point, explore those things and just make sure that it's done in a safe manner.

**Chelsey Judge, PhD:** [00:15:02] Thank you. I appreciate that. And then, we can move on unless, Dr. Prakash, do you have anything to add?

**Ruchika Prakash, PhD:** [00:15:09] I don't.

**Chelsey Judge, PhD:** [00:15:10] Thank you.

**GG deFiebre:** [00:15:10] Okay, great. Thank you all so much. So, so we do get a lot of questions about vitamins or other supplements. Are there any vitamins or supplements that are recommended for people with NMOSD to take? You know, a lot of folks with NMOSD might be on medications, like for example, rituximab. Are there any specific supplements that are recommended for people who are on some sort of immunosuppression, or also any supplements that should be avoided? Dr. Blackburn, if you want to start.

**Kyle Blackburn, MD:** [00:15:41] Sure. And, and kind of as an introduction to vitamins, I think the first thing whenever it comes to working with the neurologist or your whoever's prescribing your medications regarding vitamins is making sure that, that we're aware if you are taking a supplement like a vitamin and kind of monitoring of certain levels of vitamins. So the reason for that is certain vitamins can actually in excess cause certain issues in the nervous system, and we can kind of talk about that a little bit more. But the first part of the question, you know, specific vitamins for, for NMOSD. The evidence probably isn't as robust as it is for a disease like multiple sclerosis, but there is some concern that patients with diseases like NMOSD, they may, they may be vitamin D deficient.

[00:16:32] So I do think it's a generally a very safe recommendation to have your vitamin D levels checked with your physicians and consider supplementing that as appropriate. There is some suggestion that vitamin D may play a role in immune health, and I think it's a very reasonable and safe thing to do as long as levels are being checked over time. In rare instances, somebody may not qualify for vitamin D therapy if they have a history of calcium problems or kidney, history of extensive kidney stones. But for the most part, most people will. That, now that being said, mega doses of vitamin D in very, very rare instances have caused toxicity in certain patients.

[00:17:14] So there can be too much of a good thing. So we have to, that's why I always recommend having someone following those levels over time. If you're staying within a safe, the general recommended two to 5,000 units a day, you're probably never going to run into trouble, but just good to have someone keeping an eye on those levels.

[00:17:31] That's probably the, the vitamin that I can say we probably feel the strongest about most people being on. There are others, and certainly your doctors may check for things like vitamin B12 deficiency or vitamin B6 levels. If you're experiencing other symptoms that, just to see if there's anything that they need to augment, it's specific to those. And, specifically with the B6 levels, I've seen a few people taking those because they've heard that it can be good for the nervous system, but B6 in excess can actually start to cause some pain and neuropathy itself. So you have to make sure that you're getting it right. I think as long as you're working with your doctors and having someone check the levels every year or so, you're, you're unlikely to run into trouble though.

**GG deFiebre:** [00:18:17] Thanks so much for that overview. And Dr. Wang, do you have anything to add or any kind of anecdotal experience also with working with patients with NMOSD?

**Cynthia Wang, MD:** [00:18:26] Yeah. I think Dr. Blackburn's exactly right. A lot of this is extrapolated from other conditions where the immune system is thought to play a role, namely multiple sclerosis.

[00:18:35] I generally try to get the vitamin D level somewhere between the 50 to a hundred range. And so I think it's always good for the patient to know what their vitamin D level was, because I think many primary care providers will think, you know, a 20 to 30 is, is fine. And I think, you know, a higher level might be, you know, supportive of immune, you know, regulation and function.

[00:18:58] So I would certainly second that in, in many other diseases, inflammatory bowel disorders, even in COVID, they've seen higher levels of vitamin D seem to be somewhat protective against sort of a dysfunctional or aberrant immune response. I add, I would add that I often, just you know, get a sense of the patient's diet as well, because if it is someone who's just not eating that, enough, getting enough of those nutrients or vitamins through our diet, I think a multivitamin is fine. And certainly you can't really, you know, extract any harm from that. And then I think fish oil, omega-3s, alpha lipoic acid, sort of the building blocks of, you know, myelin and other, you know, kind of neuroprotective, antioxidant type vitamins are, are less likely to cause any harm.

[00:19:44] I get a little bit more skeptical when it's, you know, kind of branded as, you know, this magic panacea to solve all autoimmune problems. And, you know, only the special formulation from a certain company, which costs a lot of money. You know, it will be the, the, the solution to your problems. But I think, you know, anything that you can get from a big box store where it's a reputable brand and you're taking it as recommended per that, in consultation with your physician, I think there's, there's probably not too much harm that can be done and potentially some good.

**GG deFiebre:** [00:20:17] Great. Thank you. And we'll, we'll dive into diet and a little bit more detail in a bit, but for now, I'll turn it back over to Chelsey.

**Chelsey Judge, PhD:** [00:20:23] Thank you. So keeping the focus on vitamins and the ones that we suggest or think about potentially for NMOSD patients, what about potential vitamins that could be detrimental to the immune system, particularly if patients are on immunosuppressive medication?

[00:20:39] I think some people are concerned about boosting your immune system and causing relapse. And I thought maybe first we could define what we mean by boost. I think as an immunologist, right, we're not really like boosting our immune system by taking vitamins. I think that you, both Dr. Wang, Dr. Blackburn did a really great job of talking about that immune regulation and balance.

[00:21:02] But in your clinical practice, how do you define that word boost and how do you discuss this topic with your patients?

**Cynthia Wang, MD:** [00:21:09] Yeah. Yeah. I think I had the same thoughts when I was looking at that question. I think that the thing about the immune system, the nervous system is they're, they're, they're such complex systems that it's, it's hard to, to know. It's, it's difficult to imagine that any one thing can, can you know, dramatically change it. But I think getting into what Dr. Blackburn and I were saying, we do know that certain vitamins in excess can be toxic, namely vitamin B6. I think people associate vitamin C with, you know, kind of a boosting the immune system. I don't know enough about that literature to make a specific comment. I, I wouldn't recommend that people just go and buy vitamin, you know, the, the, the medication vitamin C and just take that all the time.

[00:21:51] I think, you know, even unstudied, that logically does not bode well with me but yeah, I think we are just so lucky that, at least in the, the field of NMOSD, that there are such, you know, effective, well-studied treatments that yeah, I think, you know, anything beyond those, I think just requires a conversation with your, your practitioner about, you know, what's the benefits and the risks might be.

**Chelsey Judge, PhD:** [00:22:20] I completely agree. I appreciate those, that, those insights, Dr. Wang. I know a bit of some of the emerging science or data behind vitamin C, obviously like a lot of interest, of course, at the start of the pandemic, as well as zinc. And there's some loose or weak science with taking vitamin C and zinc to potentially help speed up recovery from common colds, but to your point, that's taking it very short term versus long-term. And then, I just think a good point is that vitamins aren't regulated in the same way by the FDA that drugs such as approved NMO treatments are. And I think that that should also be considered by patients and, you know, just to keep that in mind. Dr. Blackburn, do you have anything else to add?

**Kyle Blackburn, MD:** [00:23:04] No, I think you've covered it pretty well too. The, yeah, whenever I see something labeled as an immune booster this, the scientist in me is a little bit skeptical about what that could mean. As you've said, maybe there is some role for vitamin C and zinc in a, in a short-term infection. Outside of that, it's, it's pretty hard to say that we have a lot of data to support that.

[00:23:26] But I don't think that there's any harm, any harm that's going to come to you from an immune system side. Many of the vitamins or minerals, I think the specific questions probably saying if I'm trying to quote unquote boost my immune system, am I, is that going to cause deleterious effects with my immunosuppressant?

[00:23:43] And I, I don't think that there's likely any harm there.

**Chelsey Judge, PhD:** [00:23:47] Thank you. And Dr. Wang had brought up diet earlier because, well, what does our food offer us? A lot of sources of vitamins, of course. And obviously, there's a ton of questions on the role of diet and immune disease, including NMO. So to this, to all of the panelists, whoever wants to start first, are there any specific recommendations or data that support a particular diet?

**Kyle Blackburn, MD:** [00:24:13] It's a, it's a good question. So I can only kind of speak from what I've kind of seen. And sometimes I speak about this in terms of kind of neurologic disease in general and brain health in general. And I don't think that a specific diet has emerged as a thing. As a particular favorite, I think there are general themes as to what a healthy diet is.

[00:24:35] A lot of those are things that we already know in general, I think, which are fewer processed foods pushing more fruits and vegetables into the diet, more fiber. Certainly that's an easy recommendation for

people that may have bowel dysfunction. Fiber can help with regular bowel movements. And making sure that you're maintaining a healthy weight with that diet is certainly helpful. There are, there is increasing research looking at the role of the microbiome and potentially the role that what you eat plays in the, the gut bacteria, that microbiome, and the potentials for how that could impact the immune system and autoimmune disease.

[00:25:15] And while we're all very excited about that work, there's, it's hard to make any firm conclusions about what to tell people about that just yet. I can't tell you to take a pill or cut out cheese and that that's going to fix a major part of your immune system or your autoimmune disease. So, for people that are curious about doing, eliminating things from their diet and trying to see if that provides any benefit to them, we generally tell them to do it in a systematic way as we would, if we were studying anything ourselves, keep all the other things constant and try to eliminate something. If that's carbs, if that's gluten, whatever you choose to do. And give it a trial and see how things are going. And if you feel that there's a perceived benefit you can continue with that.

[00:26:00] But right now, I think in general, I don't have, other than recommending a heart healthy diet, the same things you hear about like Mediterranean style diet, more fish, more vegetables and more fruits, those kinds of things. I don't think I have a specific food to avoid or a specific food group that I would strongly avoid.

**Chelsey Judge, PhD:** [00:26:19] Thank you, Dr. Wang as a clinician, do you have anything else to add?

**Cynthia Wang, MD:** [00:26:23] No, I think that's definitely a lot of them. Great information that Dr. Blackburn provided. And I tell my patients similar things. And I think, you know, maybe just again, so much of this is individualized that maybe if someone were to, to, you know, make an effort to, to explore their diet, then trying to keep a log of what they're eating and seeing if there's any patterns that emerge, you know, if dairy or gluten or something specifically leads to more fatigue or pain or weakness, then for you that makes a lot of sense to try to avoid those foods and see if that helps you. You know, less processed foods, more plant-based diets seem to be, what's kind of, you know, supported by, by science. But I think it's really important for people to know that, you know, I think diet is a really hard thing to change very quickly.

[00:27:12] So I think people who have embarked on like a very, you know, significant rapid change into what they're eating, they might see some improvement, but it's not sustainable. So I think making small changes that you think that you could do over the long-term is very important.

**Chelsey Judge, PhD:** [00:27:30] Great. Thank you. And then Dr. Prakash, do you have anything else to add or another perspective?

**Ruchika Prakash, PhD:** [00:27:36] Sure. I think I, what I would like to say is that the National Institutes of Health are investigating, or investing a lot of resources in the field of nutritional sciences. So in the next 10 years, I believe we're going to have a ton of data about different kinds of diets and their impact on various chronic conditions.

[00:27:56] As of now, there's very limited research on different diets, whether it's the Mediterranean diet or the paleolithic diet or the keto diet and how it impacts autoimmune disorders. The strongest evidence is for Mediterranean diet improving cardiovascular health. And I think that has been repeatedly shown, but there's very limited evidence for autoimmune disease. Excuse me, there's very limited evidence for autoimmune disorders.

**Chelsey Judge, PhD:** [00:28:26] Thank you. And, I just have one follow-up question because I know it's very trendy on social media or different groups within the autoimmune community and that's the fast-mimicking diet. And if you guys had anything you wanted to add to that?



**Cynthia Wang, MD:** [00:28:41] Is, is that the, the like periodic fasting diet?

**Chelsey Judge, PhD:** [00:28:44] Yeah, I think there's a lot of different takes on it. Whether it's you eat within a certain, time restricted eating, like you eat within an 8-to-12-hour window, or you fast for two days a week, you know, there's a lot of different takes on this, but it seems like it's bubbling up everywhere.

**Cynthia Wang, MD:** [00:28:59] Okay. Yeah. I have to admit, I don't know that literature very well, so I can't speak to it. You know, I think like what we're learning about the microbiome is that maybe, you know, the population of the bacteria in your gut might have a role in immunity, in, you know, neurochemicals that you're, that you're exposed to.

[00:29:19] So. I can't really speak to any specifics, but yeah, I'm thankful that there's a lot of research, a lot of interest in these fields and hopefully, you know, in a few years we'll be able to provide some better guidance.

**Chelsey Judge, PhD:** [00:29:34] Thank you. And I'll turn it over to GG.

**GG deFiebre:** [00:29:37] Sure. Thank you. So we also have gotten a lot of questions, especially as, you know, medical marijuana has become legal in, in various states, about medical marijuana and whether it can help with pain or other symptoms like spasticity, for example, in those with NMOSD. Has there been any research that has been done on this? Any particular strain that might be better than the others? And then what about the use of CBD oil or CBD lotion? Dr. Wang.

**Cynthia Wang, MD:** [00:30:05] Yeah, you know, I I looked into this a little bit in preparation for the podcast. There's some studies, you know, they're all, they're relatively small, but at least some have found that at least the ones that they use in their studies, which were probably, you know, vetted by the people who ran the study, were safe and well tolerated and may have a role in alleviating pain, spasticity, and sleep disturbances.

[00:30:28] This is actually MS, sorry, multiple sclerosis data. I didn't find anything within NMOSD specifically. Yeah, I think again, it becomes sort of this question within like things that are not well-regulated nutraceuticals and CBD are probably among those, in my opinion, that there can be a lot of variation in, you know, what's actually in, in those substances. Within my field of pediatric neurology, CBD has been FDA-approved for certain epilepsies and for those epilepsies that could be covered. But I think it gets to, to kind of the question, is it, is it really effective? Is it effective for all people? And then, is it going to pose a financial burden if, you know, if it, even if it's helpful for you to sustain that?

[00:31:12] So I think that's some of the questions that raises. But to my knowledge, it hasn't been studied specifically relating to NMOSD.

**GG deFiebre:** [00:31:21] Great. And Dr. Blackburn, any additional comments or patient experience?

**Kyle Blackburn, MD:** [00:31:27] Sure. So I'm happy to comment a bit more. So there, there have been people looking at the role of marijuana products. And then, there's a variety of them. Some of them are sprays. Some of them are actually inhale, inhaling cannabis. Looking at the role for THC and CBD containing products, specifically in managing pain and spasticity, there are, there is some signal in studies in recent years that there may be some impact on pain, neuropathic pain, but they, nothing very large or rigorous in the NMOSD world or the neuroimmunology world in general I would say.

[00:32:08] There, interestingly, when it comes to spasticity, they've been studying that specifically as well. And there actually is a therapy called Nabiximols, which is a kind of cannabinoid-based product that has been approved in the UK for spasticity and MS and is actually being studied in clinical trials in the United States.

[00:32:29] So this is a regulated product that's being manufactured specifically for spasticity. I suspect over time we will start to, we'll start to see other specific therapies or other potentially medications using the same pathway, exploring their role in pain. We just have to see what the studies show.

[00:32:49] I always caution people whenever they're considering using cannabis itself or a CBD-containing product or a THC-containing product of some type, just about a few things. One of them is whenever they look at these studies, they do see about 10% of people having some adverse events. And some of these are actually symptoms that our patients with NMOSD experience pretty frequently, the big ones being some of the main cognitive issues.

[00:33:17] So issues with their thinking and memory perceived issues with thinking and memory and fatigue. Both of those are pretty high on the list. So, I think it is important to keep those in mind whenever you're going to start using products like this. Ultimately, I think the best thing is just to keep your doctors informed of what you're doing as well.

[00:33:36] I don't think any physician is going to look down on someone for looking for a medication to try to help with pain or spasticity. But keeping us in the loop about what you're doing in those regards is hugely helpful. And we certainly value hearing your experience as well.

**Chelsey Judge, PhD:** [00:33:52] Thank you. We're going to shift from that very hot topic to another hot topic, I think. And something that I think patients maybe actually, or a good takeaway too, which is exercise, low impact exercise, helping patients with NMOSD. I've seen, you know, a lot of different headlines and science articles related to different types of exercising, including low-impact aerobic exercise, yoga, aqua therapy.

[00:34:20] Maybe we'll start with some of the research that might support this. So Dr. Prakash, do, what can you tell us about exercise?

**Ruchika Prakash, PhD:** [00:34:29] Sure. So exercise training, I feel like it's been one of those interventions, especially when you think about complementary interventions, has been investigated the most in the context of various clinical conditions.

[00:34:43] And I think for the most part, there's promising support for exercise training to impact a number of different metrics, metrics of symptoms. So for example, some of the work that we have done has looked at how exercise training can impact processing speed and working memory in individuals with multiple sclerosis.

[00:35:04] And we have a trial that's right now funded by the National Multiple Sclerosis Society, where we're looking at the effects of simple, low intensity physical activity training, and how that impacts working memory in individuals with multiple sclerosis. Our preliminary results show that people who are, who have higher levels of physical activities, so physical activity includes the whole spectrum of activity that you could be doing. So these, this could be low intensity exercises, right? Or not exercises, but low intensity physical activity, which means that you are walking more to places as opposed to taking your car, or if you're taking your car, you're parking your car really further out from the grocery store so that you take more steps to, all the way to moderate intensity exercise, something that gets your heart rate up in the moderate, moderate intensity range. And then really vigorous intensity exercises that you would do on an elliptical or a treadmill.

[00:36:02] And all of these, including low intensity exercises, have been shown to benefit what's called cognitive functioning or just your brain's ability to think. We also know, not in, I think there's work done with MS patients as well, but that exercise training can also help reduce symptoms of depression.

[00:36:22] And I know that psychiatric disturbances, especially issues of depression and anxiety are elevated in NMO patients. So exercise training has been shown to be efficacious in, in, in that domain as well.

**Chelsey Judge, PhD:** [00:36:35] Thank you, Dr. Prakash. Really appreciate that. Dr. Wang, Dr. Blackburn, sorry, can you offer any clinical perspective or any recommendations or experiences you've seen with patients?

**Kyle Blackburn, MD:** [00:36:48] I absolutely think that exercise is probably one of the easiest things we can recommend of all of the interventions we'd recommend to a patient because we know just how beneficial it is to you, your heart and, and your body and the whole, even if you have to significantly modify as Dr. Prakash was talking about. Just even simple measures for exercise can have a huge impact on the heart and just your overall conditioning, which I, which I believe is also going to have an overall impact on your overall wellbeing.

[00:37:21] Certainly looking at the overall health of the brain, I think that it's very easy to recommend, as Dr. Prakash was saying, lower decreased rates helping with depressive symptoms, potentially having also positive effects on the cognitive function as well. Certainly one of the most effective treatments for fatigue in patients has been a sign of a graduated exercise program as well.

[00:37:46] So it's one of those low hanging fruit that I think everyone can and should do to improve their life.

**Chelsey Judge, PhD:** [00:37:54] Great. Thank you. I really appreciate that. Before we move on, Dr. Wang, anything else to add?

**Cynthia Wang, MD:** [00:38:00] No, I agree with them the other panelists. I think, you know, sometimes exercise seems like such a, you know, overwhelming thing that, you know, especially if you deal with chronic pain and fatigue and you may not be mobile enough that, that could just seem like a really tall order, but I think just maybe discussing with your clinician, kind of getting a sense of what you're able to do and figuring out maybe with a, under the guidance of a physical therapist, you know, what is achievable. What, what are good, you know, achievable goals.

[00:38:34] How can you set goals for improving or increasing your, your exercise duration or intensity. I think it's just a good place to start and maybe, you know I think exercise can be a lot of different things for different people, but at the end of the day, if you can increase your heart rate, get a sweat built up, it can be, it can be anything. So I think trying to, to think creatively about ways that engage you and, you know, bring you joy, whether that's, you know, introducing music to your exercise routine, you know, doing something else while you're exercising. I think the more you can kind of build on other things you enjoy and also get that exercise, the better, and again, more sustainable that activity can be.

**Chelsey Judge, PhD:** [00:39:17] Thank you so much.

**GG deFiebre:** [00:39:18] Yeah. Thank you. And so we did get a question about Reiki. Has this, is this a tool that's useful for people with NMOSD, are there any benefits or risks, or have any of your patients used this particular technique?

[00:39:32] Dr. Wang, if you want to start.

**Cynthia Wang, MD:** [00:39:35] Yeah, I had to kind of look it up because I've heard of it, but didn't really know much about it. And as sort of, you know, I don't want to be a broken record many of these things have not been well-studied. But I think what might be interesting with this technique and many other techniques is, you know, introducing some mindfulness or some meditative qualities.

[00:39:53] And I know that's Dr. Prakash's area of expertise. So yeah, I think again, anything that encourages wellness, you know, feelings of wellness and health, increased motivation and joy. And I think that's sort of this type of thing that we're hoping to explore more rigorously. But I think she probably can speak more to, to that from some of the things that, that important research she's done.

**GG deFiebre:** [00:40:16] Yeah, Dr. Prakash, if you wouldn't mind talking a little bit about mindfulness and...

**Ruchika Prakash, PhD:** [00:40:20] Sure. I'm happy to talk about mindfulness. Well, so I think mindfulness meditation, it's something that I feel like has been used in the Western culture since the early 1980s, but it's only been in the last decade or so that it's been really gaining prominence in the scientific world. And now we are conducting very systematic studies where we're looking at the effects of mindfulness training on different metrics of health. And, you know, one of the things that I should mention, especially since I happen to be mostly a researcher, is that when we're thinking about complementary approaches, and in fact, I think when we think about efficacious approaches in general, we want to make sure that there is solid evidence and which is what a lot of us experienced when we were looking at the literature based on complementary therapies and NMO, which is that there's very little research that has been done with NMO patients when it comes to complementary approaches. But in general, there's very limited research on complementary therapies as well. And when research has been done, it isn't as strong as what you would want to be able to tell our patients that yes, you know what, this is what you should be doing in order to improve your quality of life.

[00:41:37] But the good news is that there are a number of trials underway where we're systematically looking at, can mindfulness training help reduce fatigue, can mindfulness training help reduce pain, can mindfulness training enhance overall quality of life? And these trials, and I think the important element of these trials is that they're being compared to what's called an active control group.

[00:42:01] Right? When we do randomized controlled trials, we basically flip a coin and randomize participants into what's called the active group, which is usually people doing mindfulness training, or a control group. Most of this research that had been done in the past would compare the mindfulness training with basically a group that did nothing.

[00:42:21] And guess which group got better? The group that did something. But now what we're trying to say is that we want both groups to be doing something. If mindfulness meets in a group setting where you're interacting with other patients that have a NMO, the control groups should be doing that as well, because we know that social support plays such an important role in quality of life.

[00:42:42] And so these trials are underway. We recently completed a study, which was comparing it to an active control condition. This was a pilot study in individuals with MS where we did four weeks of mindfulness training, right? It's just about an hour and a half per week where we met with our clients. And then 30 minutes a day, they were invited to engage in mindfulness practices.

[00:43:05] And we found that the group that engaged in mindfulness training as opposed to the group that did cognitive training was the one that got really, that showed reduction in what's called emotion dysregulation. And this is a transdiagnostic factor that underlies the psychopathological disorders of depression and anxiety.

[00:43:25] So mindfulness training has a, has lots of promising support when it comes to reducing depression, anxiety, reducing fatigue levels. Don, ED at University of Washington has been doing phenomenal work on this. And then there's a lot of strong evidence for mindfulness training helping reducing chronic pain.

**Chelsey Judge, PhD:** [00:43:44] Thank you. Thank you so much, Dr. Prakash. It's just like so much information in a positive way that I think we can really all use, even those of us who don't have NMO. You brought up the importance of social support, and I wanted to see if you could elaborate more on the, o the importance of social support, social connection.

[00:44:03] And then also for those who are not active meditators, can you, can you elaborate also on mindfulness? Like what does that look like? Does that mean like you're sitting in a chair in silence or is it yoga or, or what does that look like?

**Ruchika Prakash, PhD:** [00:44:19] Sure. So I'll answer the second question first and then I will come back to your first question.

[00:44:26] So, you know, mindfulness, it's, it's such an elusive construct. And I have been working within this field and I am an active practitioner of mindfulness and have been doing so for the last 12 years. And I feel like with every passing year, I peel, a layer peels off for me. But really when you think about the definition of mindfulness, it's all about cultivating present moment awareness.

[00:44:51] So all of you who are attending this podcast right now have taken the time and have the intention of listening to this podcast. But our minds can be distracted in all sorts of various ways. Right? We're thinking about dinner or we're thinking about an argument that we had earlier in the morning, and that takes us away from present moment.

[00:45:11] And mindfulness is all about intentionally committing to the present moment and doing so in what's called a nonjudgmental and accepting way. Right. I've done a lot of work with clients who have chronic pain, and when I, when we talk about experiencing present moment awareness and experiencing what's going on in the present moment, it's not always the most pleasant.

[00:45:35] And they often find themselves do not, either not accept it or judge it in really harsh ways. And so the framework that we tend to use around mindfulness is really about doing so with an attitude of acceptance and non-judgment. Now it's a skill that needs to be cultivated. And I always use the analogy of exercise because that's a literature that, or that's research that I've done a lot of research in exercise training as well.

[00:46:00] So if you wanted to go to the, go get fit, you wouldn't just go to the gym once, once in your lifetime and say, "You know what I am fit for the rest of my life." So I call it a lifestyle approach, and it's really about cultivating this on a daily basis. So we teach mindfulness in the context of either a four-week intervention or an eight-week intervention, where we do a lot of didactics around mindfulness training.

[00:46:27] But then also give our participants and our clients active meditative practices that they're invited to engage in every day. And it doesn't have to be an hour long because lots of people think that that's a big barrier, because how am I going to find one hour to engage in these stress reduction practices?

[00:46:45] And even 15 minutes can be enough. And in fact, when COVID hit last year, I made a lot of the materials that we've developed in my lab over the last 10 years, we made them publicly available on a YouTube channel. So they are freely available for anyone to go in and engage in mindfulness practices. Even, you

know, there are lots of videos about defining mindfulness or these attitudinal foundations of acceptance and non-judgment, so if anyone's interested, I would be happy to put that in the chat button.

**Chelsey Judge, PhD:** [00:47:18] Thank you so much, Dr. Prakash, that would be greatly appreciated.

**Ruchika Prakash, PhD:** [00:47:21] Sure.

**Chelsey Judge, PhD:** [00:47:23] And so moving on, still with the focus, of course, on complementary therapies, we've really, you know, emphasized questions on complementary therapies throughout the NMOSD disease course in general. But do either of you clinicians, Dr. Blackburn, Dr. Wang, do you have any thoughts on complementary therapies during acute relapse?

**Cynthia Wang, MD:** [00:47:43] Yeah, I'm trying to think about how to answer that question. Yeah. I guess one thing that sometimes we've done is in, in myelitis patients, is functional electrical stimulation, which I would argue actually has a lot of evidence, but I think sometimes isn't as widely used as it, as it could be.

[00:47:59] So I think that's something that can be helpful in, in instances where, you know, we're trying to promote the reconnection of maybe, you know, pathways that have been injured from inflammation. But yeah, I think during the acute period there, there's a lot of things going on. You know, there's, there's a lot of things that have been well studied and proven that, you know, sometimes when we're trying to see patients, they're, they're getting, they're already getting physical therapy, occupational therapy, speech therapy. They're getting, you know, multiple studies. So I think it's sometimes a hard time to fit in more than, than those things. But I think that's an excellent question and probably worthy of, you know, people thinking about it more.

[00:48:38] Yeah, I don't know. Dr. Blackburn, can you, can you think of anything that has been used in those circumstances?

**Kyle Blackburn, MD:** [00:48:44] You, you know, I was striking out as well as I was trying to think of any of the therapies we've talked about today in regards to an acute treatment. Certainly we'll have people going through aggressive therapies often during an acute relapse.

[00:48:59] But I, whenever it comes to these things, I have a little bit less rigor in the studies for them. I think we tend to lean on the traditional Western approach that we've been using for years. In treating an acute relapse and in preventing relapse, those are the things that we have been able to show that work.

**Chelsey Judge, PhD:** [00:49:20] Thank you. And then following up with Dr. Wang, when you talked about the functional electric stimulation, I hope I got that right. Would you say that that type of complementary therapy would be applicable in the hospital for someone who's having a relapse? Or once they're out of the hospital, or both?

**Cynthia Wang, MD:** [00:49:38] Yeah. I think it's something that's been practically or logistically difficult to do during the acute medical hospitalization. But in our children's hospital, I worked very closely with our physical medicine rehabilitation physicians and you know, oftentimes as a patient is finishing their steroids or their plasma exchange for an acute exacerbation of NMSOD, we're thinking about the next step, which is to get them into an acute rehabilitation hospital or center to continue, you know, that recovery process. So sometimes I think that can be, discuss it, it really varies geographically and by medical center. But I, I know for sure, you know, we, we're big proponents of functional electrical stimulation at our, our rehab hospital.

[00:50:20] And yeah, I think that is still kind of an inpatient setting where, where those techniques are used, utilized frequently.

**Chelsey Judge, PhD:** [00:50:28] Thank you so much. And I'll shift back to GG.

**GG deFiebre:** [00:50:31] Great. Thank you. And then are there any other complementary therapies that we haven't talked about, that you know, that you would recommend, or, you know, that are currently being studied that might kind of come up in the future?

[00:50:43] I'd like to start with Dr. Prakash.

**Ruchika Prakash, PhD:** [00:50:47] So, I don't think that this is as much of a complementary therapy as, but it's a factor that I think has been found to be unequivocally associated with good health and improves quality of life. And this goes back to Chelsey's question, is about social support and connectedness.

[00:51:05] And I'd like to talk, just briefly mention, if you all haven't heard about something called blue zones, then I would recommend just Googling that and you'll find some really interesting information. But it's really this idea that National Geographic Channel, and this was a research that they did well a decade ago or so, they identified seven blue zones in the entire world.

[00:51:29] And these were areas, or these were zones, which had the highest proportion, highest number of centenarians, basically people living over the ages of a hundred. And they tried to identify what were characteristics of these communities that predicted such high life expectancy. And one of the things, and there were several factors that they found that included physical activity, you know, some aspects of the Mediterranean diet.

[00:51:56] But one thing that they found consistently across these communities was social connectedness and social community that we can, for that, that these communities had some, and there was this one, there's an Island in Japan called the Okinawa Island. And over there, people have friendships. People are put together with other people when they're at the ages of four or so.

[00:52:19] And then they live up until 104, 105. So they've been with that community, that group of people for about a hundred years or so, it's just a beautiful documentary and I think really establishes the importance of social connectedness. And then following these and anecdotal evidence, even in research studies and especially research with animals has shown that social connectedness, animals when they're left with other animals or in cages, tend to do much better in terms of brain health, as opposed to animals that are left alone. So I have a big plugin for always, and especially during these times of a pandemic where we find ourselves in our silos, alone at home, making more of an effort to reach out to our family members and friends and making sure that we still find a way to stay socially connected, even if it is through attending these podcasts and having these virtual communities. I'll stop there.

**GG deFiebre:** [00:53:16] Great. Thank you. That was, that was great. And then Dr. Blackburn and Dr. Wang, do you have anything to add, kind of from a clinical perspective? Any sort of therapies that we haven't really talked about, that you've spoken to your patients with about?

**Kyle Blackburn, MD:** [00:53:28] Yeah. there is one that came to mind when I saw that question. The, there is a technique that certain physical therapists will do called dry needling which is actually can be effective for some people's pain. So, it's done by a conventional practitioner if you will, a physical therapist, but is a technique that may be akin to acupuncture in some ways, but can be helpful for people's pain.

**GG deFiebre:** [00:53:57] Great. Thank you. And Dr. Wang, anything to add?

**Cynthia Wang, MD:** [00:53:59] Yeah. And yeah, I'm so glad about the topics that have been covered, including, you know, mindfulness and social connectedness. I think, you know, some people, when they say they don't have the time to embark on some of these more intensive approaches, I think even just kind of having a practice of breathing, being intentional about your breathing can be really effective.

[00:54:20] There's a practice called diaphragmatic breathing that I think one of our social workers, Katherine Chapman covered in a prior podcast. And I, I think you know, even if you can just do that, you, you take some deep breaths and, you know, just kind of, you know, get away from some of the stress and anxiety of any situation, can be a temporary good practice to build into your, your daily life.

[00:54:43] And then in regard to social connectedness, I think many of us in the medical community have found that in some ways it's actually eliminated some barriers or perceived barriers that we had, that we couldn't, you know, have meetings or be at all kinds of meetings with people from different parts of the country or across the world.

[00:55:01] And I think you guys probably can speak to, to some of the, the programs that are in place from SRNA that provide, you know, a platform for people to connect who may have the same condition and be able to relate to each other, to each other much more. I think being part of a rare community you know, naturally lends, you know, a desire to, to know people who've been through your, your own experience.

[00:55:22] So I think it's great that those types of programming is available, and I would encourage people to really look into those things.

**GG deFiebre:** [00:55:29] Great. Thank you.

**Chelsey Judge, PhD:** [00:55:32] And I just wanted to ask the one other question. So after all of this, to the clinicians, do you ever recommend or support choosing one or choosing these complementary therapies in place or in cessation of long-term or immunosuppressant therapy?

**Cynthia Wang, MD:** [00:55:51] I think my, my response is no, especially when it comes to aquaporin positive NMOSD. I think all the data supports that that is a very aggressive condition, and relapses can be extremely detrimental and cause a lot of physical and vision disability.

[00:56:08] So yeah, that's a pretty hard no for me. But you know, I think again every, everybody's case can be different. I think one of the questions was seronegative NMOSD, and I think that's an area where we don't know enough about, in cases where that may be actually a different condition such as anti-MOG disease, there may not be such an important role of you know, immunosuppression from the get-go. So, yeah, I think it depends on the diagnosis, but when it is aquaporin-4 related NMOSD, I pretty much counsel my patients that regardless of the perceived risks of these treatments, it is much better to be on them than to risk a, another, or a relapse.

**Kyle Blackburn, MD:** [00:56:48] And I would agree. I think it's very hard to take something that has been shown to be beneficial and particularly with a disease that can be so devastating as an aquaporin-4 positive NMOSD, to recommend that in most people. Where I think some of the complementary treatments can substitute traditional pharmacology, pharmacologic treatments may be in, in, certainly in pain, in depressive symptoms, and in fatigue.

[00:57:16] I think that there's a huge role for those to be done in concert or in, or standing alone for those symptoms. But I think for controlling the disease activity itself, I think I always recommend some sort of



immunomodulating medication.

**GG deFiebre:** [00:57:35] Thank you so much. And then, you know, we're at the end of our time, so I just wanted to open it up and see if you had any last thoughts. Dr. Prakash, we'll start with you.

**Ruchika Prakash, PhD:** [00:57:43] No, I think we've covered quite a comprehensive area of complementary approaches. I think as I was looking up research for this podcast, it clearly seems to be the case that there is more research on complementary therapies and approaches that's needed for NMO patients, especially as we are to think about people as an integrative whole and addressing not just symptoms but improving overall quality of life. So I'll end on that note that we need more research in this area.

[00:58:11] Thank you for having me.

**GG deFiebre:** [00:58:13] Thank you. Thank you for joining us. Dr. Wang, do you have anything to add?

**Cynthia Wang, MD:** [00:58:18] No, I think, yeah. I think all of us provided I think unique perspectives. Yeah, there's just not that much known in this field. And I think it's really important for, you know, individuals who have the condition to engage with organizations such as your own and their, their medical providers so that we can start thinking about, you know, where, where are the needs of the, the patient population not met. And then hopefully that will lead to more research of the important questions to people who have this condition.

**GG deFiebre:** [00:58:48] Thanks so much. And Dr. Blackburn.

**Kyle Blackburn, MD:** [00:58:51] Well I think we've covered a lot of ground. But, but to kind of emphasize what I was saying earlier, any time, I think complementary therapies may very well have a good role in, in, when used appropriately. I think it's always great to talk with your doctors about them and make sure that everyone's in the loop, but I think that you'll wind up being much happier and safer that way.

[00:59:13] And I appreciate you all having me today.

**GG deFiebre:** [00:59:16] Great. Thank you all so much. And thank you Chelsea for co-moderating with me. We really appreciate you taking the time today to talk about such an important topic. So thank you all so much.

**Cynthia Wang, MD:** [00:59:26] Thank you.

**Chelsey Judge, PhD:** [00:59:28] Thanks everybody.

**Kyle Blackburn, MD:** [00:59:30] Thank you guys. It's been a pleasure.

**Ruchika Prakash, PhD:** [00:59:32] Thank you.