Explaining NMOSD to Others

You can listen to the audio of this podcast at: https://youtu.be/IkKd6B_4C9g

[**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: [00:00:59] Welcome to the ABCs of NMOSD Podcast Series. This podcast is entitled explaining NMOSD to others. My name is GG deFiebre from the Siegel Rare Neuroimmune Association.

[00:01:11] ABCs of NMOSD is made possible through a patient education grant from Viela Bio. 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.

[00:01:39] For today today's podcast, we were joined by Dr. Chelsea Judge and Sumaira Ahmed. Chelsea Judge, PhD, immunologist is sister to Connor and scientific advisor with the Connor B. Judge Foundation, which raises awareness and research funds for NMO and related autoimmune diseases. She works as a medical science liaison in the MS field for Sanofi Genzyme and is passionate about communicating science.

[00:02:03] Sumaira Ahmed is a seronegative NMO patient from Boston, Massachusetts. She founded The Sumaira Foundation for NMO in 2014, just two months after getting diagnosed. She currently serves as the organization's Executive Director and is committed to finding a cure for neuromyelitis optica.

Chelsey Judge: [00:02:20] Hey, I'm really happy to be on the SRNA's ABCs of NMOSD. I'm elated to be here and share a little bit about my glimpse and understanding of NMO and what it's like to at least, live, see someone, who... I never know what word to use... battles, is a warrior, or just lives with NMO. I'm personally touched by NMO because my brother, Connor, was diagnosed with NMO nearly six years ago. He was just 22 at the time. We thought he was a very healthy, young, vital man, but he started to get these very weird symptoms that, I'm going to be totally frank, no one in our family really took seriously. He kept complaining of vague eye pain and lower back pain. And he was over the summer. And so now we know that he was bringing this out, but he was working as a landscaper and we just, we thought like, 'Oh, okay, come on, calm down. Like, it's not that bad. Or you're just trying to get out of work.' Very ashamed to say that. But it ended up being, of course, NMO. And he was going to multiple doctors and they kept calling it vague inflammation, and I'm sure a lot of NMO people can understand that frustration. And so finally, it culminated just a few weeks later with him literally waking up one day completely blind and paralyzed below the waist. And so he had to literally just with his upper body, shove himself off the bed and crawl to the car, and his girlfriend at the time drove him to the ER. We're very, very blessed or lucky if that's the right word, to live in Cleveland where there's a lot of major research and health systems, including the Cleveland Clinic.

[00:04:02] So at the ER, actually a part of his differential diagnoses, the neurologist on hand actually said the word, the letters NMO. No one knew what that was. It was a complete shock. And he's kind of been just coming to terms with that over the past five to six years, and I think now we're finally at a decent state of acceptance with it. My brother, thank goodness, with great attentive healthcare, and I would say very passionate family members, got that swift diagnosis and treatment to that first, very serious relapse or attack. He recovered from the blindness and the paralysis, but of course, like all NMO patients, he still lives with a lot of those pernicious, invisible symptoms and risk of relapse.

[00:04:46] My mother and I were obviously deeply touched by this experience, and we immediately went to Google searching for foundations that supported NMO. And we only could find at the time the Transverse Myelitis Association, which is now of course, SRNA. And then we realized there's Guthy Jackson on the West coast. And this was at the time that Sumaira was just starting her foundation, and we didn't even know about it yet. So we felt like we had to contribute something, do something for my brother and patients like him where we were, again, bringing together the major research and healthcare teams in Cleveland.

[00:05:25] So we started a foundation on behalf of my brother, the Connor B. Judge Foundation, where we raise awareness and research funds for NMO and related autoimmune diseases. And I have a weird background that's, I guess, very ironic. I was doing my PhD in immunology at the time of Connor's diagnosis. And so I act as now a full PhD immunologist, as the scientific advisor for our foundation, and try to communicate to my best of my ability about the science of NMO and where our research funds should be allocated.

[00:05:55] So that's a little bit about me. Sumaira, tell them your amazing story.

Sumaira Ahmed: [00:06:01] Hi guys, so Chelsea, it's a pleasure to be on another podcast episode with you. So to those who don't know me, my name is Sumaira. I am an NMO patient and the founder and executive director of The Sumaira Foundation for NMO.

[00:06:22] I was 25 years old when I first lost vision and got afflicted by all these very, very sudden and random symptoms that I almost initially thought was a manifestation of my imagination. But thankfully I live in Boston, I work in healthcare and very quickly we were able to determine that I had NMOSD. And so, two months after getting diagnosed and, you know, while in bed rest, I sort of decided, like Chelsea and her family, that there were so many gaps in the awareness of this disease that I felt I needed to do something about it. I have a public relations background. As I said, I worked in healthcare, I still do. And social media was a strength personally and professionally. So putting all of those things together and realizing that awareness was a desperate need for this community, I decided to start The Sumaira Foundation for NMO. And quite frankly I didn't know what I was doing, and sometimes I still don't, but six years later, I am both proud and excited to say that we raise awareness for the disease. Actually the disease spectrum, so we now also do work for MOG. And we share patient stories, we fund research through our grants. And just as an organization, we're very passionate about creating a positive community for patients and their caregivers. And in terms of my health, knock on wood, I have been stable for about a couple of years. I have suffered about 10 relapses and six years of dealing with this, but this is the longest I've gone without any issues, and I'm super grateful to that.

Chelsey Judge: [00:08:16] Oh, Sumaira, that is an amazing statistic. It's Thursday at noon that we're recording this, so I don't have any champagne with me, but like I would definitely toast to that.

Sumaira Ahmed: [00:08:26] Thank you. Yeah, no, it's definitely a relief too. And I think, you know, in a way, a lot of patients look at my story as inspiration for their own, and I can motivate them to live life beyond their diagnosis. So hopefully my recovery and my stability empowers them and reinforces the fact that we're not just our diagnosis. We can live a life beyond that.

[00:08:56] **Chelsey Judge:** [00:08:56] Yeah, Sumaira, I think that's a really good point. I think that you also are just an amazing example and I really like your guys' mantra of illuminating the darkness of NMO.

[00:09:06] But I also think that you're really good at validating the valid and not, hmm, what is that, like, toxic positivity. You're really good at like, 'you know what, yeah, this sucks, but you know what? Here's what we can do about it, or here's the silver lining.' And I think that you strike a really good balance with that.

Sumaira Ahmed: [00:09:22] Chelsea you're sweet.

Chelsey Judge: [00:09:24] I thought that maybe, just very high level, we could just talk a little bit about how we, like you and me, Sumaira, to kind of communicate what autoimmunity and what NMO is to obviously the public or even just our friends and family.

Sumaira Ahmed: [00:09:38] Totally.

Chelsey Judge: [00:09:40] So even though I could get super into weeds of the immune system and why autoimmunity happens, you know, like I can nerd out over that. I think a really good way of describing autoimmune disease is what probably most people are familiar with, it's really when your immune system goes haywire, becomes erratic, and starts attacking its own body. And, you know, we see this as the result of genetic predispositions, but you know, it's not just genetics. We know that there's a lot of environmental factors that contribute to autoimmunity.

[00:10:17] One of the biggest, not just for NMO, is smoking, right? Or environmental toxins that creates this erratic, dysregulated immune system that loses its brakes, so to speak, that results in autoimmune disease. Does that sound about right to you, Sumaira?

Sumaira Ahmed: [00:10:34] Absolutely. But you're the scientist. You can, you can explain this much better than I can.

Chelsey Judge: [00:10:40] I just want to make sure that it's digestible. And then with NMO specifically, the immune system starts attacking components of the central nervous system, right? Which is the brain, the spinal cord, and also part of the eye, the optic nerve, that communicates between the brain and the eye. And immune cells of your body start attacking things that look like enemies to them, but they're obviously not. A big one that we know that's identifiable in NMO is aquaporin, those water channels. Antibodies start to attack aquaporin four in NMO. And then we're learning that there's also, and not just NMO but also MS, attack against a type of myelin. So it's like the fatty substance that coats nerves. So there's myelin, a protein Myelin Oligodendrocyte Glycoprotein or MOG. That's another big candidate that we see that gets attacked in NMO that leads to the blindness, to the paralysis, to the other neurological impairments that we see in NMO patients.

[00:11:41] So again, we could get into the weeds of that, but I think that just having that gist of, what is autoimmunity and what is the basic science of NMO, can maybe partially explain some of the different symptoms that patients might have.

Sumaira Ahmed: [00:11:57] Absolutely. And I think this is the perfect segway into that.

[00:12:01] So, I guess from a patient's perspective, I can offer some insight on to what happened to me, but of course, what happens with patients who have this disease. So, NMO manifested for me via vision loss, numbness and tingling in my extremities, and, not something I would put on my dating profile if I had one, but bladder issues.

[00:12:26] Unfortunately, I know that that's a pretty common one to come across our community. But, you know, as I've said time and again, I definitely suffer from something called survivor's guilt because, relatively speaking, I definitely have it really good compared to some other patients. And, you know, there are patients that've lost their mobility, they've lost strength in their muscles in their extremities. You know, in addition to bladder incontinence, unfortunately there's also bowel incontinence, that's prevalent in this disease. There are cognitive issues, you know, which has led to a lot of these patients being unable to continue their education or, you know, pursue careers that they wanted to.

[00:13:17] And, you know, this is why I say all the time that I have it so good because I, even with my issues that I had, I never had to sacrifice those things. And then that's where the survivor's, the survivor's guilt definitely kicks in. So, I mean, Chelsea, would you be comfortable talking about some of the issues that Connor dealt with?

Chelsey Judge: [00:13:40] Yeah, at least just what I know what he'd be comfortable with me talking about. One, I just, again, I want to validate the valid that, you know, you handle this with so much grace. And I understand rationally what survivor's guilt is, but it also troubles me to hear that people feel that on top of living with a chronic illness like NMO. I find myself as a sister feeling guilt that my brother has it, but I don't have it, that kind of thing.

[00:14:04] So it's the closest I can get to understanding that. But I feel, Connor's biggest problems outside of the obvious ones with his first attack of paralysis and blindness, is the residual neurological damage that caused him bladder/bowel issues, predominantly incontinence and bladder urgency.

[00:14:23] I know he'll like kill me... I don't know if he'll kill me if I say this, but we can check with him. You know, he also experiences sexual dysfunction, right? Like that's a very, very, very, very common symptom in NMO and MS. The pain, neuropathic pain to some extent in his legs, spasticity is a big one. He still has some visual issues, like eye pain. Obviously, it gets worse with the heat. And then I think a really pernicious one is fatigue. I think that this is, yeah, probably the most invisible or people just write it off as, like it'd be like me, a healthy person who's in her late twenties, early thirties, be like, 'Oh yeah, man, I worked really hard. Like I'm tired too.' Like, no, no, no, no. That's not the same thing. You have to compare the kind of fatigue that patients with autoimmune disease have to something like, 'Hey, you know when you were like completely wiped out when you had the flu? Well, it's like that, but my whole life off and on.' And that's partially because of the inflammation that is going on inside your body attacking your nervous system. But people can't, yeah people can't see that.

Sumaira Ahmed: [00:15:26] Oh, and I'm so glad you brought that up because that's something that I personally have a tough time understanding and believing, even though it's my own body. And I think it's hard for other people to understand that too. The fatigue is so real. I was always kind of a sleepy head growing up. Like I loved naps, and I honestly, I could sleep anywhere and everywhere, but it's more than the sleep component. You know, the fatigue is just like, sometimes it is just so hard to get out of bed. And it's not even that my eyes are closed, my body is so tired. And I've been so hard on myself about this, because I'm like, you know, you didn't do that much activity, but like you said, it's the inflammation that's happening, you know, underneath our body, inside of our bodies that we can't see. So it's kind of, this plays mind games with I think both the patients and of course with other people, because, of course it's invisible to us, but it's invisible to others too alongside let's say the visual symptoms. So, you know, I have optic neuritis. I lost about 60% of my vision permanently on my right eye. So what does that mean? It's not that it's blurry. It's just that my field of vision has decreased by 60%. So where I can see out of, which is now only 40% of what the average person can see out of, it's much smaller and yes, it is blurry.

[00:16:59] So when I have what my friends call a geriatric font size, and sometimes they make fun of it just in jest, because they forget that I can't really see as well as they can. So often people will look at my phone and be like, 'Oh my God, Sumaira, your font is geriatric size.' And I'm like... And then they realize in that moment, like, 'Oh my God, it's because she can't see.' But it's because they don't remember because I don't look like a quote unquote blind person.

Chelsey Judge: [00:17:28] You do such a good job to hide it too.

Sumaira Ahmed: [00:17:32] Yeah. Because I just don't want people to feel bad for me, and I also don't want others to judge me. And I have to admit that sometimes these, for a lack of a better word, this disability sometimes makes me feel a little bit insecure, especially in a professional setting, because I don't want people to think that I am incapable of getting something done or accomplishing something because of my limited vision.

[00:18:02] So just some tidbits around the invisibility of this. So I can't even imagine what other patients go through. But I definitely experience it on a much more limited capacity than some others, but it is a real thing and it's something that everyone in our community struggles with.

Chelsey Judge: [00:18:20] Right. I think that's a really good point. Well, you bring up a lot of really good points, but that, you know, what you cope with is a significant disability. I mean, there's no other word for it, right? But there's a spectrum of experiences or like a disability scale. And we have to be compassionate to all of them, whether you're at like the lower end of it or the higher end of it, whether it's visible or invisible. We're all humans. We're all going to inevitably go through something. We should show compassion for those who are going through something right now.

[00:18:49] My husband, although we're talking about NMO, he has MS. He's legally blind from it. So he has limited vision. He can see out of like a little bubble, but he's legally blind. But, I mean, I'm his wife and I forget because he does such a good job of compensating for it, that I find myself sometimes being insensitive. So I think it's a learning continuum. And again, it's about seeking to understand and seeking to be compassionate.

Sumaira Ahmed: [00:19:14] Couldn't agree more. And I think we all need to come from a place of compassion, whether it's small or not. You know, there are so many other ailments, whether autoimmune or not, that are just invisible, and you just never know what somebody is going through. So I think this is a lesson that can be applied. Try to come from a place of compassion.

Chelsey Judge: [00:19:40] Amen. Totally agree. And I think that brings us to another good point in our conversation is, you never know what someone's going through. And when you have a chronic disease like NMO, that means they're going through this for life. There is no cure. Even if we have now, thank goodness, three different FDA approved treatments that can help to manage at least their relapses. That's all wonderful, but it's something that you have to deal with for life.

[00:20:05] Like, I don't even... the minds. The coping mechanisms that one has to develop to handle that. Wow.

Sumaira Ahmed: [00:20:15] Totally. I cannot tell you, Chelsea, how many times, even family members: A. Forget that I have this, and B. Forget that I have it for life. You know, I'll see extended family members sometimes, and they'll be like, 'Oh, you look so good. So, so is it over? You're done with it? It's cured?' And I'm like, 'No.' I mean, I don't know how many more ways I need to tell you, how many languages I need to say it, but yeah, exactly. I wish, but no, I'm stuck with this. And, you know, when I tell people that I am on treatment for life and that too, some of it is chemotherapy. They're like, 'huh? But you don't have cancer.' And that just opens a whole other can of worms that, you know, chemotherapy, immunosuppressive therapy is not just for cancer. And I think that is an educational token that we need to just put out there for everybody. NMO patients, MS patients, other rare disease patients, autoimmune diseases patients, we all use chemotherapy drugs.

[00:21:20] The dosing may be different. But it is chemo. And it doesn't mean I have cancer.

Chelsey Judge: [00:21:25] Right, right. I think it's just cancer's like, [sighs] the most public, or like, I feel it's so silly, but people have heard of cancer, right? Or they've been affected by it. Whereas I think a lot of other diseases to most people are vaguer, more foreign to them, that they don't appreciate that these types of treatments are used also to target the inflammation that are seen in these autoimmune diseases to prevent relapses and prevent those, you know, the immune system's attacking the body from itself. So yeah, it's not understood well enough, and that's why we have to keep talking about it and making the public more aware.

Sumaira Ahmed: [00:22:02] Of course, of course. And I think we're doing just that. And I will say that from, you know, six years ago from when I first got sick, and even just observing the community, the education around that and the awareness around that is moving ever so slowly. But it is moving in the right direction. And I'm grateful for that.

Chelsey Judge: [00:22:21] Yes, definitely. So Connor has had NMO almost six years now. And when he was diagnosed, there were no FDA approved treatments. And now we have three, all targeting some aspect of the immune system. Again, to help reduce that inflammatory attack towards the body. And even just, I've heard of anecdotal stories mixed with the data that just shows, you know what? These patients, you know, from a historical perspective are doing so much better now. But that being said, we still haven't tons of progress to make.

Sumaira Ahmed: [00:22:52] Yeah. And I think, obviously progress includes understanding the cause of why it happens and of course, wanting to get a cure so that we don't have to be medicated for the rest of our lives or quote unquote chained to a pole for the rest of our lives. So I'm very hopeful for that. I hope that, you know, a cure is in our lifetime. Which, at this rate, Chelsea, like we keep saying, we have three FDA approved drugs in 18 months.

[00:23:23] That is unheard of. That is historical. And maybe I'm overly optimistic, but what that tells me is that we're closer than ever, and it's possible we may see it in our lifetime and be able to take advantage of that.

Chelsey Judge: [00:23:37] I couldn't agree with you more. I'm very hopeful. I just look, right, I'm from the immunology side, and I see all the great progress that's been made there. And then I think the next missing piece is, okay, we can target the immune system, reduce the inflammation, but can we do things to repair the damaged nerves? And that research is really exciting and promising. And I have my fingers crossed and my prayer hands and everything else that we'll see something, again, within our lifetimes.

Sumaira Ahmed: [00:24:03] Totally, totally. When I was younger, I say this now I'm in my thirties, but I got NMO when I was 25. And when I was younger, I used to have a really tough time not knowing what caused it. And I used to blame myself because I just couldn't find any other reason. I'm like, 'why did this happens to me? I was totally fine before. Like, did I do something? Did I eat something? Did I get it because I traveled or whatever? You know, your mind explores every possible option when you're that desperate for answers. And it was tough to cope with not knowing anything about anything, or really not being able to see the light at the end of the tunnel.

[00:24:52] But just to go back to what we were saying about the FDA approvals, I don't feel that way anymore. And I can speak on behalf of the community. I don't know that many of us feel that way anymore.

[00:25:03] We have had so much hope given to us in science and research, and the community is growing from a patient perspective. Even neurologists and scientists who are invested in this. You know, at the AAN conference, I think it was virtual this year, they had said that NMO is the hot topic in neurologic research. And that, even if it's just a headline, makes me feel so good about our future.

Chelsey Judge: [00:25:34] Yes. I think that from a scientific perspective, I say this to Connor all the time, I hate that you have NMO. It's frustrating, but it is so fascinating. And it has, I mean, it is really catapulted. I think neuroimmunology research, right? Because we have a biomarker, AQP4, for at least the vast majority of NMO patients. That's allowed to create like an idea around personalized medicine of the identification of biomarkers, targeted immunotherapies. And then also giving us a better understanding of the relationship between the immune system and the nervous system to drive us towards better treatments and a cure. So a thousand percent agree with you. Last year it was called the year of NMO, and my God, what a true statement.

Sumaira Ahmed: [00:26:19] Yeah, I couldn't agree more. We're in a good place. And as I always say, it's corny, but our future really is very bright.

Chelsey Judge: [00:26:28] It is, it is. And, you know, yeah, it truly is. And I look at something like MS, where it's similar. You know, there's so many different treatment options for MS, all of which target some part of the immune system. But I just thought, just highlight that while MS I think is a more, the public is more aware of multiple sclerosis, right, as another neurological autoimmune disease. It is very different from NMO, even though I know a lot of NMO patients have been misdiagnosed with MS. And it's really important that patients get the proper diagnosis because treatments, some of them for MS can actually either have no effect for NMO patients or can make NMO worse. So really important to get the right diagnosis.

[00:27:17] Multiple sclerosis typically affects mainly the brain, but there are definitely spinal cord involvement as well. Whereas it's the opposite for NMO. We see a lot more spinal cord involvement, more so than the brain. But again, it still attacks the brain as well, it's just different proportions. And then obviously, we don't see AQP4 reactive immune cells in MS. That's specific to NMO. So NMO used to be called like really severe MS. And now we sometimes hear it's the crazy cousin of MS. But it's really important to get a proper diagnosis because, as all NMO patients know, the attacks that NMO patients see can be much more sudden and drastic than in MS, where MS is more of a slow-moving, progressive, accumulating disease. So really important to know the difference.

Sumaira Ahmed: [00:28:11] And I think that that's a great segway into, how do you explain NMO to others? And so often I catch myself saying, think of NMO as the cousin to MS. Because, you know, like cancer, MS is so widely recognized by the average person and NMO is not. So you have to almost explain it to people.

Chelsey Judge: [00:28:36] Paint a picture.

Sumaira Ahmed: [00:28:36] Exactly. And explain it to them in a way that they'll understand, which is MS. And so it's like MS. It's a cousin to MS, but it's treated with cancer drugs. Is that how I have caught myself before, but it helps people understand that why we're on chemo. How does this disease act, you know? And so I find that that's a very simplified way of explaining it to, you know, family, friends, primary care doctors who have never heard about this.

Chelsey Judge: [00:29:12] That's another good point, that you're educating the clinicians sometimes. Right?

Sumaira Ahmed: [00:29:16] Absolutely. Absolutely. I mean, who knows the disease better than the person who suffers from it? Right? And, you know, the doctors, they only know about, especially when it comes to PCPs or physicians who are not

Chelsey Judge: [00:29:35] MS specialists and neuroimmunologists,

Sumaira Ahmed: [00:29:37] as connected to it. Right. Or if it's an emergency medicine doctor, you show up to the emergency department with symptoms and they have to triage you. It's important for us to know how to explain it so that they triage us correctly.

Chelsey Judge: [00:29:52] Yeah, to make sure that they listen to you.

Sumaira Ahmed: [00:29:54] Exactly, because I can't tell you how many times I have heard that in our community, patients have been turned from, you know, the emergency room or their PCP or whoever, because it was deemed as a figment of their imagination or a panic attack.

[00:30:13] I've heard that so many times. And honestly it really breaks my heart because you think about, well, what if it had been treated as it should have been when they first presented in the emergency room or their doctor's office? Maybe wouldn't have progressed so, so far right into the disease, but we're learning as we go, right?

Chelsey Judge: [00:30:35] Yep. And then you bring up really good points. And like the reality of the consequences are just that. If you're not treated earlier, you might have long lasting neurological damage. So those are really good points and, you know, I've had one of those instances where I went. It was actually for my husband's MS. He was having a relapse; it was very obvious. He was having numbness and tingling in his limbs, so his arms and legs. And so that meant, boom, spinal cord involvement. Anyway, we go to the ER. I have a PhD in immunology. He's lived with MS at that point for nearly 10 years. This is classic.

[00:31:10] And we're being treated like we're drug seeking for high dose steroids. I don't know anybody that does that. And, you know, we were put through the ringer, even though, you know, by all accounts, we're like these very respectable, well-educated people who know how to handle this disease. And we didn't receive prompt care. We actually had to leave the ER and seek outside treatment. You know, it's astounding, and it really requires a high amount of advocacy for your loved ones, but also for yourself.

Sumaira Ahmed: [00:31:37] I couldn't have said that better myself, Chelsea. I think more than ever, it's so important for us to learn how to advocate for ourselves and for each other as a community, especially in the world of COVID. You know, there are so many different things happening medically right now. And we need to be able to differentiate our symptoms, especially if somebody is having a flare up in the emergency room where there are COVID patients who are being prioritized. I'm not saying that they shouldn't be, but the value of us being able to articulate the severity of what these flare up symptoms can do in a long-term perspective is very important.

Chelsey Judge: [00:32:19] Yes, absolutely. And I think, kind of on the flip side, when you're talking, like you were highlighting earlier when you talked to people and they don't like, for these invisible symptoms or they don't quite get it, or if you feel guilty for your NMO, like you brought it on yourself. I, you know, feel for that, because that's just obviously not true. But I understand how you can, you know, warp yourself in that, where people kind of put it on you, like, 'well, haven't you gotten better yet? You're on treatment.' You have to deal with the stigma of that and constantly communicate to people why that diet is not going to work for me. It won't cure my NMO. Or like, trust me, I've tried X, Y through whatever different things, and this is the situation.

Sumaira Ahmed: [00:33:02] Do you know how many times I've been asked if I'm going to end up in a wheelchair? And I know that it comes from a place of concern sometimes, but people do ask me more often than you'd think. And it's so interesting because, while I'm a pretty unfiltered person, I don't know that I would ever ask someone that, especially somebody who has a neurologic condition. But it just, all of this to say that the education still needs to be elevated even amongst the lay public, which is why we all do what we do. It's possible I may end up in a wheelchair, and I never really know how to answer that, but I say it's because, it's because, you know, I am lucky to live in Boston. I got treated very early. I got diagnosed early. So hopefully that mitigates the whole, you know, extremity disability. But. So explaining NMO to others. Yeah.

Chelsey Judge: [00:34:02] Yeah, it's really complicated. And, like you say, you know, you use MS as an example, so people have that in their heads of, you know, an older family member that they saw growing up who was in a wheelchair. You know, it's very different from where the current landscape is for NMO and even MS patients, where, again, we have a number of high efficacy treatments that target the immune system to shut down or reduce the inflammation that damages the nervous system. And you know, the data is just there for both and MS patients, that if you use these highly efficacious treatments early on and you get a swift diagnosis, you just... it's intuitive as well. You don't have to have a PhD, but if you are getting the diagnosis early and you're treated early with something that's known to work, your prognosis is going to be much better than if you received a later diagnosis and didn't get on a treatment early. So again, it's so important to educate and empower patients with this information and then highlight the hope is very real.

Sumaira Ahmed: [00:35:05] So real. And I want to end my segment of this by just saying to patients and caregivers that, you know, of course to advocate for yourself. And when explaining the disease to others, maybe sometimes it's helpful to compare it to something that they know, because that's how our brains work. And also nothing to be embarrassed of.

[00:35:29] You know, I used to be on a dating app or whatever a couple of years ago, and I used to feel insecure and I'm like, 'Ugh, do I bring it up? Do I not? When is the right time?' Now I wear my diagnosis with so much pride, because like you had said earlier, you know, it's, it's something that, it's a positive thing in my life. Despite having symptoms, despite having flare ups, despite having to, you know, be on treatment for the rest of my life, it's made me better in so many ways as a human being, and it's given me so much purpose. And I no longer feel shame of telling people. I wear it with a lot of pride. And I think that all of us, you know, we're of course at different stages of the disease, but there comes a time when you realize you're so much more than your diagnosis. And I am fortunate to have reached that turning point a couple of years ago, and I wish the same for everybody else.

Chelsey Judge: [00:36:30] Sumaira, I've said this many times when I've recorded with you or talked to you via Zoom, but I wish I could hug you.

Sumaira Ahmed: [00:36:36] Oh!

Chelsey Judge: [00:36:37] I only say this little story because you brought up online dating or dating apps. So again, this is about NMO, but because of NMO, it opened up, with my brother, it opened up this whole world where, you know, just inundated with NMO information and learning about patient advocacy and everything like that. But I went on Bumble a few years ago and actually met my husband that way. And he at that point in his MS space was very open about it. And that was one of the first things he ever told me about himself. And I immediately knew a little bit, way more about him than if he hadn't told me his diagnosis.

[00:37:13] I knew the adversity that he had to face. I knew the kind of persistence and grit that he had to develop in order to cope with something like MS or NMO. And it made him to me like more endearing. I respected him more because I immediately knew a lot about him just because of that. If again, it's not his identity, but it did shape him. It did shape you. It did shape my brother. And, you know, you have to go through battles and it sometimes will make you bitter, but along the way, overall, you know, it really shapes your character development.

Sumaira Ahmed: [00:37:45] I couldn't have said that better myself. It gives us some edge. I like to think of myself as an onion now. I have so many layers to me, and NMO is one of them. Right? I'm so proud to be a part of this community. I'm so proud to say I have survived everything that I've survived, and I'm really excited for what the future holds.

Chelsey Judge: [00:38:08] I am too. Thank you so much, Sumaira. I look where my brother was just six years ago where we were just wrought. We didn't know what to expect. We were terrified. I feel like we went, we did go through all of the stages of grief, and I think there's a lot of denial and bargaining, but now we're definitely at acceptance, been there for a while. And I just see obviously where the treatments have gone and being a part of clinical trials -that's Connor. And just seeing how one, of course, his NMO is relatively stable. And to see him be in a good place means the world to me, obviously, and my family. And to know that that's the story, hopefully, for a lot of other NMO patients. Just, I don't know, makes us want to fight harder, but it definitely just warms my heart. I don't have any other, I don't have better words for it.

Sumaira Ahmed: [00:38:54] I think you said it. Sometimes the, we're saying things without saying, so you hit the nail on the head. As always, it was a pleasure to speak to. I can't wait to see you in person, hopefully once all this passes. And let's keep making a difference. Let's keep illuminating the darkness of NMO and, you know, fighting for all of our patients to make sure that they get access to the care that they need, the treatments that they need, getting more FDA approvals, you know, more stories out there, and finding a cure. I know were going to do it.

Chelsey Judge: [00:39:26] Yes, thank you Sumaira. Thank you Sumaira, thank you SRNA. Totally agree. This has been awesome. Stay healthy.

Sumaira Ahmed: [00:39:32] Yes. Thank you.