

NMOSD Stories:

Kristen

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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: [00:00:59] Hello, and welcome to the ABCs of NMOSD podcast series. Today's podcast is NMOSD Stories: Kristen. My name is GG deFiebre from the Siegel Rare Neuroimmune Association. ABCs of NMOSD is made possible through a patient education grant from Viela Bio.

[00:01:17] 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's podcast, I was joined by Kristen, who is someone who is diagnosed with NMOSD.

[00:01:45] Hi, and thank you so much for chatting with me today about your story and experience as someone with NMO. So to start, do you mind just briefly introducing yourself?

Kristen Hewitt: [00:01:57] Absolutely. So my name is Kristen. I am an NMO patient in San Antonio, Texas. I am an SRNA Support Group Leader, so I'm pretty active in the NMO community. And I'm also a single mom, I work full time, and then I volunteer quite a bit, so I stay pretty busy.

GG deFiebre: [00:02:16] Yeah, for sure. Thank you. And thank you so much for being a support group leader. So in thinking about kind of the beginning of your, you know, diagnosis, your onset with NMO, at what age did you start experiencing symptoms, and what were these initial symptoms that you had?

Kristen Hewitt: [00:02:34] So my first known symptoms, and I say known symptoms because after I got my diagnosis, kind of looking back at my med, my medical history, there was another incident that potentially was NMO, but at that time we didn't know I had NMO, we didn't think about it. So my initial symptoms were, the best way I have to explain it is when you walk outside in the sun and then you come into a dark room and you kind of have those spots and those lights flashing. And I was 24 years old. My job had just moved me to a desk that looked out the window.

[00:03:07] And so I thought it was from staring out the window while I did my work and then kind of walking around the building. Over time, it progressed, it got a little bit worse. And eventually the actual vision started

to completely disappear and kind of blackout and close in, so to speak, on me. And so those were my initial symptoms at 24.

GG deFiebre: [00:03:29] And then you said that there may have been something before that. What, what were those, what was that experience like that you think may have been initially NMO as well?

Kristen Hewitt: [00:03:38] So right after I had my son, so a little bit more than a year before the vision issues had set in, I was having narcoleptic episodes. But I had had a really tough pregnancy, and I was on my own with the newborn, and so they kind of chalked that up to life circumstances. But I now know after getting the NMO diagnosis that that could have been a symptom of NMO. And so with those, I, I remember just losing 30, 45-minute chunks of time. And so I would be watching a TV show and be in the middle of it and then suddenly wake up and that show is over and I'm halfway through another show, or reading and all of a sudden waking up and, and have not been reading for a period of time. And so that was kind of, that's kind of the incident that was a year prior to my vision issues that I kind of think probably was also NMO related.

GG deFiebre: [00:04:35] Got it. And then, so, so what happened next after this, you know, you said when you were 24, your vision started going, what happened next? Did you visit an emergency room?

[00:04:44] Did you see your primary care physician or other physician? Just kind of walk me through what happened next?

Kristen Hewitt: [00:04:50] I actually went to my optometrist. I figured it was vision related. I work on computers. Like I said, I was looking out the window, so I thought maybe it was something to do with that.

[00:05:00] So I went to my optometrist. She ran some tests and basically told me, "you need to get seen immediately." She picked up the phone, called an ophthalmologist. The ophthalmologist saw me, said, "you need an MRI right now," called the imaging place, and said, "you need to get her in today." So basically in one day, I went for my optometrist to my ophthalmologist to an MRI. And then it just kind of stalled out.

[00:05:25] And I remember at that point kind of freaking out a little bit. And I worked in the medical field. And so I kind of used that to my advantage, and I called and had my imaging results faxed to me. And I saw the MRI and it said that there was a lesion. So then of course I freaked out a little bit because I have no idea what I'm looking at.

[00:05:45] But the ophthalmologist would not see me. And finally he called and said, "I've never seen anything like this before. I don't feel comfortable. I'm continuing to treat you. I think I want to send you to..." So I live in San Antonio, so we have the University of Texas Health Science Center here. He's like, "There's a teacher there in neuroophthalmology, I want to send you there."

[00:06:07] So I called, made an appointment with them. It was going to be a couple of weeks out. And during that time span, my vision continued to get worse. I remember one day elevator doors closed on me because I tried to walk in them, not seeing them close from my peripheral.

[00:06:22] And I picked up the phone and I called, and Dr. Carter, the neuroophthalmologist, actually worked me in before clinic one day, because my vision was continuing to get worse. At that time, he went over the MRI results, talked a little about the lesion, we talked about it being demyelinating. And if you read my report, the radiologist also had notated it did not look like multiple sclerosis. He says that it was demyelinating, but it was not, it was not the typical multiple sclerosis demyelinating.

[00:06:58] At that time, because I only had the one lesion and I had no other symptoms, they basically said with my age, it was possible that it was a fluke and that they would monitor me. They did run some labs. I think they did the aquaporin-4 test back then. They tested to make sure that I didn't have any kind of infection that was potentially causing the lesion or anything like that. They also discovered I had a Chiari malformation during my MRI, so I was not able to go for a spinal tap.

[00:07:27] So I was not able to do a spinal tap and do the additional testing that they normally would do with that. So we made the decision to monitor for a year or monitor every year. And so after that, I just continued to get MRIs until I had what would be my second attack. And in between, I had a couple of like minor flares of optic neuritis, but it was just, it was eye pain.

[00:07:51] I never lost my vision again. I never had any other issues. So for the next three years, I did not have an official diagnosis. I didn't meet diagnostic criteria for anything at that particular time. For both multiple sclerosis and for NMO, you have to have more than one lesion to meet the diagnostic criteria. And so I got to be in limbo for three years until I had that second lesion.

GG deFiebre: [00:08:13] Got it. And then, during this whole diagnostic process, did they do any of the blood tests for, you know, aquaporin-4 or the MOG antibody as well?

Kristen Hewitt: [00:08:22] So, I don't recall specifically if we did aquaporin-4. I know that we did not do MOG. I tested for MOG about a year after I got my official diagnosis. So about three years after that first attack, I started having like tingling and numbness on the left side of my body, specifically my face. I noticed it quite a bit on my face because when I would touch my face, like if I was sitting at my desk and like put my hand on my cheek, I could feel like that sensation of my face being asleep, kind of tingling up my, up my face. It would start with my chin and go all the way up to my forehead. At that time, my, the neuroophthalmologist I had been seeing who had been following me sent me for an MRI, found another lesion. And at that time he was planning to diagnose me with multiple sclerosis and was going to write me a prescription, and it was going to be one of those self-administered shots.

[00:09:12] And I told him, I didn't think I could do that. And so he then sent me to, within the UT system, the MS clinic there. And when she saw my images and stuff, that's when she looked at it and said, "I don't think you have MS. I think you have an NMO. She did send me for the aquaporin-4 test at that time, and I was negative.

[00:09:31] And then about a year later, we did test for the MOG. I don't think it was commercially available when I went through my initial diagnosis, because that was back in 2017.

GG deFiebre: [00:09:41] Yes, that's definitely a, you know, more new, you know, test that's that's available to folks at this point. So I know you said that you were kind of waiting for this diagnosis in between attacks, right?

[00:09:52] You're waiting for that second attack to kind of confirm the NMO. So did you have a diagnosis at the time, or what, what did they explain to you? You know, what your, what your diagnosis was potentially at that, at that time?

Kristen Hewitt: [00:10:04] At that time, it was just unspecified demyelination. So they didn't give me any kind of formal diagnosis. If you go back and you look at my medical records from that time, they all said unspecified demyelination.

GG deFiebre: [00:10:18] Got it. And during this time, were they giving you, were you getting MRIs of your brain and spinal cord and optic nerves, or were they doing any sort of other diagnostic tests other than that?

Kristen Hewitt: [00:10:28] I did yearly MRIs of my brain and optic nerve. At that time they did it, I hadn't had any symptoms of transverse myelitis. And of course not having a diagnosis, they didn't really have a reason to order the spinal MRIs. So I, they were doing yearly optic nerve, optic nerve and brain MRIs.

GG deFiebre: [00:10:49] Okay. And then, you know, what was your experience kind of with the medical system, you know, during this experience? What was your experience like?

Kristen Hewitt: [00:11:02] I think I got very lucky. So the initial kind of being bounced around in the beginning and having the ophthalmologist not want to call me back and not want to see me, that was definitely frustrating. But looking back, I'm kind of grateful that he made the call that he did, because it meant that I went to the medical center here that's at the teaching school. My neuroophthalmologist that I got referred to is relatively well known. My primary care doctor, when he found out who I was seeing, I found out he actually went to school and learned for my neuro-ophthalmologist.

[00:11:35] So he's been in the field forever. He's well-known, and he was just great at making sure he followed everything. He followed me for three years. I think back to it, you know, he could have, after one year of having a clean MRI and not having a second one in that first year, he could have easily discharged me, but he didn't.

[00:11:53] And when I wasn't comfortable with the diagnosis that he gave me when he diagnosed with multiple sclerosis, you know, he immediately sent me to the MS clinic and got me set up with them, and they got me in quickly. And so at least for my, I know I went a couple of years without a diagnosis, but I also know I didn't meet diagnostic criteria at that time.

[00:12:14] So it would have been hard to have given me a diagnosis. But none of my doctors gave up. They continue to monitor me, and they all acted very quickly when they, when things did happen. And so from that perspective, I think fully have had an easier time with the medical system than I know that some people have had.

GG deFiebre: [00:12:31] Okay. And then, so when you were, when you were experiencing these acute attacks, I know that they're the kind of two that you can pinpoint for sure. And maybe earlier ones, you know, that that may have been attributed to the NMO, but you're not sure about. For the, sort of the acute attacks that you've had, what treatments did you receive? Did you receive anything like steroids or IVIG or plasma exchange? And if so, did they help or, or not? And did you, how did you work with your physicians to kind of come up with a treatment option?

Kristen Hewitt: [00:13:03] So the very first one so the vision lost back in 2014, the neuroophthalmologist put me on oral steroids. And I think it was like a four to six week course where I, I tapered off slowly. And during that timeframe, I did regain my vision. It was slow. But by the time I stopped the steroids, I had fully regained my vision. The second attack, at that point, we did not give me steroids initially, just because we sent me for the labs for aquaporin-4 and things like that.

[00:13:34] But once I had done all of the labs and everything, we, I was sent for steroids and that was fairly straightforward. They sent me for IVSM - IV solumedrol - that particular time, I did three days and then I did a taper after. And again, I saw improvement relatively quickly from those. The IVSM worked much faster than the oral steroids.

[00:13:56] I had a lot of side effects with the oral steroids both times. And so I don't take those anymore. But I didn't even have to really ask for treatment. The, the first time the neuroophthalmologist prescribed me the oral steroids right away. And then with the second one, I did ask, you know, "what is our plan for treating

kind of this immediate flare?" And they told me they were going to send me for IVSM. So I didn't really have to push much as far as treatment during my, my actual flares.

GG deFiebre: [00:14:24] Okay. And then did you go to rehab at all after this, or any sort of like occupational or physical therapy?

Kristen Hewitt: [00:14:32] I did not require any kind of therapy in both of those cases and actually even the attacks that I've had since then, they've been primarily with sensation or vision loss. I haven't really had a whole lot of issues with mobility.

GG deFiebre: [00:14:48] Okay. And then what residual symptoms do you currently experience and how do you manage them?

Kristen Hewitt: [00:14:55] So with my vision, I have light sensitivity, and I don't see certain colors the same way. For those I just am a little bit more cautious about like driving at night. Sometimes my kid gets frustrated, I'll tell him to go pick something up and tell him it's pink and it's really red. And so we've kind of had to work through his patience on some of that kind of stuff.

[00:15:17] The biggest issue that I have is with like the sensation. So the left side of my body from about my waist up. If I'm tired, if I get too hot or anything like that, I have like this tingling, almost like my, my face is asleep feeling that'll kind of flare up. And then I had about a year later after, after that attack, I had one where I got like a really bad burning sensation in my right leg in my calf.

[00:15:44] And so that's another one that I tend to have like some flare ups of that, that feeling of like the back of my leg feels like it's on fire and my leg gets real heavy. So I can't do a lot of physical activity. I try not to push myself too far because I definitely start to feel some issues with my, with my leg, from that.

[00:16:03] When I bought a house, we actually set the house up to where, because I can't see in the dark. So like a normal person's vision eventually adjusts to the darkness and mine does not. So we set up the house with motion-activated nightlights. So that way it's not overwhelming when I walk into a room, but I at least have some light so that I can navigate through the house in the dark, if I get up in the middle of the night or anything like that.

[00:16:25] But that, those have been kind of my major residual symptoms. And then of course the normal fatigue and stuff like that.

GG deFiebre: [00:16:32] Okay. Yeah. Well, and then motion sensors light, this sounds like a really good idea as well.

[00:16:37] So, you know, we talked a bit about the acute treatment. So I know you, you did receive steroids for, you know, during the onset. But are you currently on any long-term preventative treatments? And if you are, which ones? Or, you know, have you switched treatments at all over time?

Kristen Hewitt: [00:16:54] So after my attack in 2017, when I got my official diagnosis, we made the decision to put me on Rituxan. We talked about CellCept and Imuran were the other two kind of big ones at that time. But because I was aquaporin-4 negative and there was still just some kind of toss up about, while my imaging looks very NMO specific, there's always that possibility that it was MS. We figured Rituxan was probably the best option because it can be used to treat either one. So that was just kind of the one that made the most sense. I also liked the fact that I don't have to remember to take a pill because I never remember to take them.

[00:17:30] I have been on it since September of 2017. We have not changed my actual prescription, but we have changed the frequency. So when I started having the flare up in my leg in 2018, we did a couple of images. And what we found in MRIs is, I was still getting lesions. They weren't enhancing, they weren't necessarily causing symptoms, but there was still some activity.

[00:17:55] And then July of this year, I started having some heaviness again in my right leg, but starting more further up with my hip. And so we just decided with me still having some activity occurring, even if it's not enhancing, and then having the kind of flare ups that I've had since starting in 2017, because I've also had, they found a little spot on the white matter in my brain.

[00:18:21] That's kind of around the area that controls memory. So I had some short-term memory issues for a while. So just because of that, we decided to change the, ituxan from every six months to every five months, which I just started this past summer kind of making that adjustment. So the hope is that maybe the increased frequency will help keep those little relapses that I was seeing at bay. If not, we will start having a conversation about potentially changing their medication.

GG deFiebre: [00:18:49] Okay. And then, you know, we did talk about your relapses. How did you recognize you are having another attack as opposed to just kind of like a worsening of symptoms? I know you said that sometimes if you are, you know, do too much or it's hot, you might have kind of a worsening of symptoms.

[00:19:05] How do you sort of try to differentiate between when you're having a relapse versus just a worsening of symptoms?

Kristen Hewitt: [00:19:12] So for me, the relapses that I have had were very different than any of the prior attacks. So my very first attack was related to my vision. My second attack was related to kind of that tingling numbness feeling on the left side of my body. The one after that was specifically my right leg in my calf area. And then the next one that I actually really noticed was the one with my leg this past year. And so they were all very different sensations. They were very different feelings, I guess you could say. And so, since it impacted a different part of my body, I knew that it was something.

[00:19:54] I also, when I was first diagnosed, one of the things that I am grateful for with my doctor is she sat me down and told me, "here's what you do, you know, if you wake up one morning and you're blind, this is what you do. If you wake up one morning and you fall over and you're paralyzed, this is what you do."

[00:20:12] And so there has always been a very open communication with her, and I always kind of had a plan of what I'm supposed to do. And so in each of these cases, I was able to pick up the phone, call her office and say, "Hey, these are the symptoms I'm experiencing." And then they kind of gave me next steps. In some cases they sent me for MRIs, in some cases like right now with COVID and everything, they actually didn't send me for an MRI for this most recent attack. They actually went ahead and just sent me straight for steroids. And so, thankfully, anytime I've had some weird symptoms, I've just, I've been able to just call the doctor and have her tell me. And there are times where she tells me that's probably not related.

[00:20:50] I was having some inner ear and some balance issues and she's like, "yeah, that's probably not NMO. Go to your primary care and, and see if you have an ear infection." And it turned out to be related to allergies and things like that. So I always check in with the office if I've got something that feels a little off.

GG deFiebre: [00:21:05] Okay. So thank you so much for kind of walking me through the, you know, your experience with diagnosis and, and treatments and kind of your, your journey up until this point. But do you

mind just talking a little bit about kind of what the most difficult part of living with NMOSD is, if you have any kind of fears or worries related to that, to your diagnosis?

Kristen Hewitt: [00:21:25] So I think at least in my case, the most difficult thing for me is just the fatigue. Especially recently, I was one of those that push through. A lot of my previous attacks... the one that I got diagnosed with the tingling/numbness feeling, I was in the middle of the biggest project of my career and we were on "go live weekend" while I had an IV attached to my arm.

[00:21:47] So I'm running around the office with an IV. And so I've just always been one of those people that has like pushed myself a little too much. And so for me, that has been my biggest challenge because I've got to remind myself to take a step back, slow down. My body can't go the way that I'm used to going.

[00:22:03] I think as far as fears, I think there's always that fear in the back of my head that I'm going to have another relapse, I'm going to have something worse happen. And sometimes I feel like I'm a little hypersensitive. You know, if something funky starts happening with my body, I start questioning, oh no, is this an attack?

[00:22:18] Or, you know, and so there's just a little bit of some fear and some concern that, you know, you never know what the, what's going to happen next, or what comes after that?

GG deFiebre: [00:22:29] Right. Right. And then, you know, kind of on the flip side of that, what are you hopeful for as someone living with NMO?

Kristen Hewitt: [00:22:37] So I'm hopeful. I mean, obviously for those that are aquaporin-4 positive, we have seen so much progress in the last 18 months with medications and research. Even just kind of having the commercialized test for MOG is another advancement. And so from that perspective, there's a lot to be hopeful for. You know, hopefully, maybe they find another antibody for those of us that are seronegative, that will help, you know, kind of form better treatments for us. And hopefully, you know, we continue to make the advancements with the medications and options that we have long-term.

[00:23:11] But I think kind of getting to, from my initial diagnosis being a little over three years ago, and even prior to that, having the kind of the limbo of not knowing what I have, there's just been tremendous leaps and bounds over the last few years. And so that's kind of, definitely gives you hope for what the future is. But it's also really cool to be alive during that time and get to witness all of that advancement.

GG deFiebre: [00:23:35] Right, for sure. And then is there anything that you wish medical professionals would know about treating someone with NMO?

Kristen Hewitt: [00:23:45] I don't know. So my core group of doctors is amazing and I'm super grateful for them. But sometimes when I go to providers outside of that, I get like two different reactions. I've got one set of doctors that doesn't want to touch me. You know, everything they do, they want to run by the neurology team and they want to make sure everything's good. And so for them, I wish they knew, like I'm still a normal person. I'm still a normal patient. Like I want you to treat me that way. And then I have doctors who, when they find out I have NMO, I become this unicorn that they want to like study and talk about and research.

[00:24:15] I saw an ENT who had read a New York Times article about NMO like two days before he saw me. He'd never heard of NMO before and now he'd read a New York Times article and he had a patient sitting in his office. And when his nurse went to print my, my stuff for me later, she couldn't make any sense of it because he had made notes about the NMO and the New York Times article and not about why I was actually there.

[00:24:36] And so I think in both of those cases, I think it's about realizing that, you know, I still have other issues. I still, you know, NMO isn't me. It doesn't define me. And so kind of understanding that I'm, I'm still a person and there's things to look at besides the NMO. And so I think that's my biggest feedback for medical professionals that are not used to seeing somebody with a rare disorder.

GG deFiebre: [00:25:01] Right, right. And then is there anything you wish your friends and family knew about NMOSD.

Kristen Hewitt: [00:25:09] You know recently, I kind of feel like they treat me like I'm not as capable. And maybe, and to some extent, again, this goes back to the fact that I need to remember that I'm not always as capable. But we were moving out of an office building and I kind of felt like the person that I was working with kept trying to pick up all the boxes so that I didn't have to pick up the boxes, and I can pick the boxes.

[00:25:30] And so sometimes I just kind of wish they... I appreciate that they think about that way. But I also kind of wish that they didn't treat me differently because of it. And so I think that would be the one, one thing with my family and friends.

GG deFiebre: [00:25:45] Yeah, for sure. And then how do you, you know, relatedly, how do you kind of explain your diagnosis or NMO to others? You know, whether that's coworkers, friends, or family, how do you explain kind of how this disorder affects your life, you know, at all?

Kristen Hewitt: [00:26:01] So I'm actually really open with most people. I don't know that I've never, I've ever had a conversation necessarily about how NMO affects my life. But I've always been really open about, I usually use MS because most people kind of know what MS is.

[00:26:17] And so I kind of use that as a way to explain what NMO is. So I'll, you know, talk to them about how I have brain lesions and spinal lesions and things like that. We do talk about medication. With COVID and kind of that whole conversation on immunocompromised, my medication kind of became a little bit more of a conversation than it had been previously.

[00:26:38] Now if I show up in the office, I get questioned. Why are you here? You're not supposed to be here. But I think for the most part, my family has kind of given, has kind of been given the high-level explanation and not necessarily a super in-depth one. And from my family, I get kind of one of two reactions and it's kind of similar to the coworker thing.

[00:26:58] I either have family that, now it's kind of a fear thing where they're super worried and they're super concerned. Or they kind of treat me a little bit differently because of it. And so I try to keep that at a, a high level and not go into too much detail because I don't want to worry everybody, and I don't want them to think that I'm, I'm not necessarily capable of all those, the things that I was before.

GG deFiebre: [00:27:18] Right. Right. And then, you know, is there anything else you, any last thoughts or anything else you want to mention that I didn't ask about, kind of about your experience of living as someone with NMO?

Kristen Hewitt: [00:27:32] Not necessarily. I think the only other thing I kind of wanted to add to kind of the conversation about family. So I'm a single mom. I was, my son was three when I had my first attack. And so he's kind of grown up with me kind of being sick. And when I talk with other patients and things like that, I know that for a lot of parents, they don't, you know, sometimes they feel like their, their kids are kind of getting the short end or they're not as able to be as good of a parent. And so I've definitely had some, some

limitations there. There's definitely days where, you know, I wish I was, you know, doing an activity with him, but I'm in bed because I just don't feel good.

[00:28:08] But one of the things that my doctors have even kind of commented on was that I have made him an active part of my journey. When we explained NMO to him, because he was super little, we, we told him I had boo-boos on my brain. And I'd come home with an IV catheter in my arm and we would talk about that.

[00:28:28] And so for me, I think one of the, the hardest parts of this journey has been him growing with that and parenting with all of those things. But I'm super grateful because now he has kind of grown into like super interested in, how does phlebotomy work? He wants to see how they draw blood, and he wants to look at the MRIs and he wants to do all of this stuff.

[00:28:48] And so that would be the one thing that for parents with NMO, kind of having an open conversation with your kids, because they're a little bit more understanding about what you're going through so you don't have to feel so quite as guilty when you're not feeling good. But also, I think it's, I think it's opened his eyes to things that at his age, he probably wouldn't have experienced before.

[00:29:09] And I love watching that interest, grow of him, wanting to see the imaging and the medical stuff and all of that.

GG deFiebre: [00:29:15] Oh, yeah. No, that's, that's a, that's a really good point as well. So thank you so much for taking the time today. Really appreciate it. And for sharing your story. You know, I know it can be difficult to talk about sometimes, but you know, we're really grateful to hear your story and, and learn more about what it's like to live with NMO. So thank you.

Kristen Hewitt: [00:29:34] Thank you so much.