

# Managing the Dread of Relapse

You can watch the video of this podcast at: [youtu.be/AUJf1hXH6pk](https://youtu.be/AUJf1hXH6pk)

[00:00:02] **Announcer 1:** "ABCs of NMOSD" is an educational podcast series that shares 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" is hosted by SRNA, the Siegel Rare Neuroimmune Association, and in collaboration with the Sumaira Foundation and Guthy-Jackson Charitable Foundation.

[00:00:38] SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at [wearesrna.org](https://wearesrna.org). This series is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease" and UCB.

[00:01:04] **Announcer 2:** Hello, and welcome to "ABCs of NMOSD." This episode is titled, "Managing the Dread of Relapse" and was moderated by Landy Thomas. Landy was joined by Heather Dawn Sowalla. Heather is an SRNA community member who is diagnosed with NMOSD. You can view her full bio in the podcast description.

[00:01:28] **Landy Thomas:** Today we are talking a bit about the dread of relapses is what I like to call it. I'm Ireland of course and I have NMO. I've had it since I was six years old, so that's been 16 years now. That's been a bit. I have with me today, Heather. Heather, please introduce yourself. Tell us who you are, what you like to do, who are you.

[00:01:54] **Heather Dawn Sowalla:** Sure, my name is Heather. I am also an NMO patient and gosh, I've had NMO we can track it back to like 2002. So, like, oh my gosh, it's been like over 20 years now. But I've been officially diagnosed for 13, which is just crazy. I live on a small farm here in Cherry Tree, Pennsylvania, and I do a lot of advocating and stuff like that. I work with different support groups. I apologize if you hear my dog she's having a dream in the background.

[00:02:37] **Landy Thomas:** It's okay.

[00:02:40] **Heather Dawn Sowalla:** So, I do a lot of that, and I pretty much just try to live day to day.

[00:02:47] **Landy Thomas:** Yeah, and for people that aren't aware, Heather is a cornerstone of the community in ways that I can't even fully express. I know as a kid, I mean, I've had it this for a long time, but I grew up always seeing Heather's posts, Heather's support. It's meant a lot as someone that has been pretty lost. Yes, there are so many great organizations, but it's been really nice to have a face.

[00:03:20] Even though I was young, I grew up with my NMO family, the Devic's disease pages, and Heather has always been the person that's champion that—always posting top of my feed every time. So, I appreciate you and I just want to make that really clear. You've done really good work, and I'm so glad that you're such an amazing member of the community to be honest because it means a lot.

[00:03:53] **Heather Dawn Sowalla:** Thanks, it's amazing and I love helping. When I first saw you, you were like this little, tiny girl with pigtails. So, it's been a long time.

[00:04:03] **Landy Thomas:** I know but people like you, people that have been in it supporting the younger generation, it makes it possible to navigate what otherwise would be kind of a disaster. So, I appreciate it. For those that are not aware, could you discuss your diagnosis story if you feel comfortable, like, the initial symptoms, and everything that you want to talk about?

[00:04:30] **Heather Dawn Sowalla:** Okay. When I first started to have symptoms, it was a lot of my eyes, and it was before we even thought about NMO. It was my eyes were a little blurry or they'd get fuzzy. And at the time I had been doing a lot of reading. I was a voracious reader. I would read a book at night, maybe more if I could. And my ophthalmologist was like, oh, it's probably just your eyes. They need a break.

[00:05:00] Let's give you a stronger prescription and life went on. It wasn't until a couple of years later that I had a flare that came out of left field. I went paralyzed on my entire right side of my body. I couldn't feel anything, and it was pretty quickly. I was working on my family farm. We were actually doing hay. I was out in the field, and all of a sudden, I was losing sensations, and it was hot outside. So, the first thought my parents had was heat stroke. So, they rushed me to the hospital, and they started doing all these tests. There was no stroke.

[00:05:38] **Heather Dawn Sowalla:** It was nothing like that, but it was progressing. It was going from like the tingling to, yeah, I can't move it, can't feel it, it won't function. And I remember a doctor coming in and taking a needle and telling me to close my eyes. I'm like, okay. So, I close my eyes, and he takes this needle, and he jabs me the entire way down the right side of my body, and I didn't feel a thing.

[00:06:02] I remember opening my eyes, and there was literally little pricks of blood the whole way down, and I was terrified. He immediately started me on steroids because what else are you going to do? Steroids, so we did that, and I was in the hospital for probably 30 days at that time. And at that point, they said, you have MS because what else could it be? It was MS. They put me on some MS drugs, and so I was kind of in that situation, misdiagnosed for a couple of years.

[00:06:38] And I had a neurologist that said, you're not getting any better you're getting worse. Because I was having flare after flare probably seven, or eight a year, and my vision was just taking a toll because at that point, I was having optic neuritis over and over and over again. So, it was like 13 years of being misdiagnosed and then being in limbo. We didn't know what it was until I finally tested positive for the aquaporin-4 antibody. And then it was like a light clicked on we knew.

[00:07:12] But at that point I had already met people in the NMO community. We had a feeling that that's what it was, but we had to wait for that concrete evidence to say, yes that's definitely what you have. And then after 13 years I tested positive and it was a relief because I knew where I fit in, and then I had an idea how do we tackle this? How do we fight this disease that I knew of, but I didn't really know of?

[00:07:45] So, right away my doctor started me on Rituxan, and we went through the whole journey of trying to find what worked for me and what didn't. It was terrifying and amazing at the same time because I got to witness that medical amazingness that these doctors do anymore. Where they can take just nothing and turn it into something.

[00:08:12] **Heather Dawn Sowalla:** I feel really blessed that even though it took 13 years, and I did keep a lot of the disability that I had from the attacks, it could have been worse. So, I feel really blessed that we did get that answer and today we have so many advancements. It's awe-inspiring really.

[00:08:37] **Landy Thomas:** Yeah, I think honestly just getting people to be able to get diagnosed quicker has been a huge deal. Because, I mean, mine took two years, but it was so like I was having flares every month and it was just agony to be in for a little kid.

[00:08:55] **Heather Dawn Sowalla:** Exactly.

[00:08:56] **Landy Thomas:** Once that aquaporin-4 blood test came out, I was diagnosed as soon as that came out, which was good. That was really what a lot of us were kind of waiting for to get a real answer because I think they were throwing around ADEM a lot from mine because it was presented so heavily in the brain.

[00:09:16] Yeah, no, your story is very important, and I know that it mimics a lot of people's stories, especially those who have had it before the blood test even existed. I'm just glad this new generation of folks aren't having as long of a wait because the worst part is not knowing sometimes.

[00:09:41] **Heather Dawn Sowalla:** Yes.

[00:09:45] **Landy Thomas:** What were your emotions going like when you were going through those beginning of your disease journey? And how does that compare to today now that it's been 20 years or 22 years?

[00:09:56] **Heather Dawn Sowalla:** Really, it was like I was on a teeter-totter. One minute I was extremely depressed. I remember going to my PCP and saying, I can't stop crying. All I think about are the bad things. What can we do? And I knew enough at that time to go to my doctor, and I felt comfortable going and saying, hey, I feel this way. And he was able to put me on some medications to kind of balance me out, but then I also started therapy and that really helped. I went from the depressed type of emotions to the I'm angry.

[00:10:38] I'm so furious I want to just stomp NMO. And then I also had the kind of, I'm accepting this, I know I have this, what do I need to do? I kind of just teeter-tottered back and forth, and it's even today I still will get into those moods where I'm happy or I'm grateful, but then I'm also depressed especially in the community when we lose members and even worse when it's a member that we lose for I don't want to say a stupid reason, but a stupid reason, like going off meds or something like that.

[00:11:20] And it's like I want to scream because it's like don't do that. And it terrifies me because if we lose them, what will happen to me one day? And that's one of the things that I've lived with for so long that it's hard. You're a young woman so you understand even the fact, that if I wanted to start a family I can't now because I had a hysterectomy.

[00:11:47] But if I hadn't, what if I wanted to start a family? And do I want my child to grow up like that? And that was just something that really bothered me throughout the years. And even now as an aunt, because I have a niece and nephew, I worry about what they're seeing and what they're going through because I feel like my diagnosis made them grow up faster.

[00:12:12] They saw me in the hospitals. They grew up with the tubes hanging. Even now my infusions I get them at home, but a lot of the times they're here with me. So, they see that, and I worry about what they'll experience growing up or if that's impacting their mental health too, because it's not just about me it's about the whole picture.

[00:12:37] **Landy Thomas:** No, I think that's totally fair. The way you said that reminds me, so my cousin we used to fight a lot when we were kids. We would be like she'd say something like, I'm wearing a skirt today and I look beautiful, and I'm wearing like pants. So, it was childish it was cute to be honest it's nothing like serious.

[00:13:03] **Heather Dawn Sowalla:** Yeah.

[00:13:03] **Landy Thomas:** But it was kind of like slightly little bullying teasing situation. But then the first day that she saw me when I was in the hospital, and I was all hooked up to all my wires and my tubes. She just cried and apologized, and I'm like you're six. Wait, no, she's seven and I'm eight, and it's like it was just a very strange moment.

[00:13:27] Both of us kind of grew up a lot in that moment where she kind of took on less of a teasing role and more like wanting to do anything to help me out, wanting to just be there for me. It was just strange. She's a good, good cousin like a sister to me in a lot of different ways. But I'll never forget the way that she saw me afterward and the way that she just kind of broke down. I know she was a kid, and I know kids cry all the time, but it felt really serious.

[00:14:04] **Landy Thomas:** Yeah, she's sweet. So, just going on to the next question. As someone who like me has been diagnosed with NMO for a long time. I'm sure you've had to deal with something that most of us are pretty familiar with, which is the fear of relapse happening again. What has that felt like to you?

[00:14:23] **Heather Dawn Sowalla:** Oh my gosh, it can be really overwhelming just wondering when. Because we always said in the community, it's not if you'll relapse but when. And so, that was always in the back of my mind like what type of relapse is it going to be? Am I going to lose my vision next time, or am I going to lose my ability to walk, or am I not going to be able to breathe?

[00:14:51] That's always been something that's really kind of always held a place in the back of my mind. And dealing with that has been really hard at times. Trying to figure out like, I did these things when I was younger where I would write down my fears. Even now, I love poetry, I love stuff like that writing. I always have a pen and paper and a notebook somewhere where I can write something.

[00:15:25] Any fear I would write it down even if it was like the stupidest thing. Or I would write a poem about how I was feeling and that really helped. And I was able to show those to my family if I felt like it sometimes. And so, they were able to understand a little bit more about what I was going through. I think that really helped at times, but I mean it's been hard. Even for as long as I've had it, at times you'd think you get used to it, but you never really do. It's always there. That worry is always in the back of your mind.

[00:16:02] **Landy Thomas:** Yeah, it feels like survival. We try and, and say we're trying to thrive, and we're trying to adjust to the new normal and live the perfect life but sometimes it is just survival. I mean, for me I think that like I don't know. It messed me up mentally for a very long time just because it happened when I was so young, and I got so depressed. Like I would not want to do anything, and I told myself, well, if this happens then it's just over.

[00:16:39] I don't want it to just be over. I don't want to treat my life like that at all. I never want to do that but it's heavy to have these disorders and I feel like that's something that we all know, but it's so hard to articulate the way it infests your life. I don't have much of a life aid or like say that I have, you know? I don't miss anything that I used to have because I was six at the time.

[00:17:11] I grew up with it and it was, I mean, it impacted choices, it impacted the shape of my life, the direction I headed. And the fear followed me for a very long time. I didn't want to live. I didn't want to do anything because I was so worried all the time that even if I did build a really good life for myself, even if I did go to college or did get married, like, I would have another flare, and it would just go away. I didn't want it to go away.

[00:17:47] So, I was like, because that's even worse than not having it is losing it. So, that mindset, which was very corrosive, it impacted me up until I was around 15 or 16 which is, that you are already hormonal enough as a teenager. I would say that was like it killed my spirit, and that was the point around 15 or 16 where I started to write. And like you, I found a lot of solace in getting it on paper and just getting it out of me because all the time that was all I was thinking about was, when is it going to happen again? What am I going to lose this time?

[00:18:32] I think that there is so much peace to be had in getting it out of your mind and onto the page or into art or somewhere. Somewhere other than just inside you and other than just self-collapsing. I think it's wonderful that you write poems. I encourage everyone to write poems. Poems are good, and they convey so much to people, and they can touch on what's really core to our conditions.

[00:19:05] Do you ever feel like there's days when the fear is worse? And do you ever have days where you forget you have NMO? Because for me I've had very rare days where I forget. Like, because it is kind of like I'm looking through a blind eye all the time, it's kind of a constant reminder.

[00:19:20] **Heather Dawn Sowalla:** Exactly.

[00:19:21] **Landy Thomas:** What do you experience for that? Is it kind of a spectrum of sometimes it's worse, sometimes it's better?

[00:19:27] **Heather Dawn Sowalla:** Yeah, some days it's worse. Like, there are a few days where I forget that I have NMO. The only times that I really forget is if we're doing something big. If I'm in a wedding with one of my cousins, I was able to put NMO to the side even though I knew I was going to get tired. It's like I'm going to put on those high heels, and I'm going to put on the dress, and I'm going to dance, and I'm going to have fun.

[00:20:00] Or days when I would be with my niece and nephew and we were doing something cool that day, like building a fort in the woods. Just little things where I'm able to get out of my own head and focus on something else so hard that I kind of forget that the NMO is there. But at the same time, I mean, it's always there. Like you, I have a blind eye. Yeah, I mean, it's hard to walk in the woods if I'm with the kids.

[00:20:29] Well, I got to pay attention because I'll fall on things. I mean but it happens. I mean but then there are those days where it's kind of hard to pull yourself up out of the darkness because you can get surrounded by the darkness. I find that especially on the anniversaries of my big attacks. When they're coming up or it's that day, I kind of don't want to do anything.

[00:21:00] **Heather Dawn Sowalla:** I want to hide in my closet in the dark, and I want left alone because I know my mind's just replaying what happened then, and it's like PTSD. It really is. What you experience trying to live life knowing what you've been through and if it would happen again. So, I mean, that's always there, and I think it's there more often than it's not and it's really hard.

[00:21:33] **Landy Thomas:** It is really hard. I know you discussed a little bit about poems great therapy, wonderful. Are there any other ways that you've been able to cope with those feelings of like dread or fear? Any kind of support systems you have? I know that our groups have been pretty good. Do you want to talk about that?

[00:21:54] **Heather Dawn Sowalla:** Sure. I think the first thing is when I'm having a bad day, I often like I've always loved to read. I mean, I started my journey thinking my eyes were bad just because I read a lot. But reading is a way that I can get out of my own head and somewhere else. So, even if I can't read a book on paper, I will turn it on my Echo Dot, and I will listen to my books.

[00:22:23] And I'm able to put myself in the place of that character, and it kind of gets me out of my own head. And I find that if I'm really stressing, I'll go to that. I'll go to that imaginary place, and I'd like to think of it, I don't know if you've ever read the book *Inkheart*.

[00:22:40] **Landy Thomas:** Yeah, I have. I like *Inkheart*.

[00:22:43] **Heather Dawn Sowalla:** How they go from the book into these magical lands. That's how I like to think about it. That's how I get myself out. I'm that main character, the pirate, or whatever. That really helps.

[00:22:57] **Landy Thomas:** I think escapism is one of the best ways to get, and I mean that in a healthy way. An escape just at least briefly just get out of your own head. Honestly, a lot of people try and bounce back so quick after they have like initial onset or recent flare and it's like, no.

[00:23:16] **Landy Thomas:** You can have a couple weeks to just scroll TikTok and do mindless things for a little bit and just get out of the, you know, you're coping right now, you're surviving. And sometimes I mean, plus books are just amazing. I think anybody that likes to dream of it should read it, and it's a good way to just break out of your shell. Honestly, I think that's totally fair. I know that with my NMO family, if people are not part of that group by now, I think they should be, such a great group.

[00:23:53] **Heather Dawn Sowalla:** Really.

[00:23:55] **Landy Thomas:** All our little support groups there, that's where I grew up with it. That's where I got a lot of support. Now with SRNA, Kathy, and all these really great organizations, I know they always have support group meetings and different things throughout the month that people just reach out to at any time, which is nice too.

[00:24:20] **Heather Dawn Sowalla:** Exactly.

[00:24:21] **Landy Thomas:** That helps. I do think that a lot of the dread that people experience it never goes away completely, but it does for someone that's like if you're a month in or two or three months in, it does get better slowly. You do have to get to a point where you could feel a little stable because at first, it just feels like you're just free falling. You need to have a sense of stability. And at that point, you just need to do anything you can to survive until you get to that point.

[00:24:51] **Landy Thomas:** And when you're there, you can start to feel as though you're alive again. And you can live a really decent life with NMO, even if it's different, even if it's harder, you can still have really nice dreams and really enjoy your life. I do think that some people see it as a death sentence and it's not. I know when I was a kid, I was told that I was not going to live for very long. If I did, I would go paralyzed or blind probably within the first five years, and it would be permanent and forever.

[00:25:27] And that was not the case. Anything that I did encounter, it was hard, but I did bounce back from it. And that's a positive and we're getting better and better with our systems of diagnosis and systems of treatment. To consider this situation entirely hopeless still is doing yourself a disservice.

[00:25:49] **Heather Dawn Sowalla:** Yes.

[00:25:49] **Landy Thomas:** It is possible to live a wonderful life. I always stress that to people because it's just it sounds so scary at first, but it doesn't. You're not alone in it and people are here that care about you, that want you to have a really wonderful life.

[00:26:10] **Heather Dawn Sowalla:** Definitely, and those support groups are so important. Even if you're not comfortable going on the Zoom calls and talking face to face. Being able to just type on a keyboard and talk to someone else that has the same disease has really helped me so many times. I know recently I took over helping to administer the My Devic's Family page.

[00:26:34] And it's like, okay, this was my home for so many years. Sometimes you have to take a break and step away, but you always come back. And no matter what you're welcome back with open arms, like, what has been going on? What is new? And that's so important. The friends and I call them family now that I've made in the NMO community, I'm closer to a lot of them than I am to my own blood family. That's just amazing, but you all understand what I'm going through.

[00:27:10] I understand what you're going through. And having that connection, I mean, it seriously makes a difference. I can't even begin to tell you just how many people I've met over the years that now it's like, yeah, they're family. You and your mom, I mean, you guys are amazing from the time that I first met you until now and it's like you changed so much, and you grew.

[00:27:43] Like you said, it's not always, it's not a death sentence anymore not like it used to be. Not everyone is going to become paralyzed or go blind, especially now if we can diagnose it early and you get on a preventative treatment. Stay on that treatment, don't go wrong. Like, that's a big thing.

[00:28:07] **Landy Thomas:** Very clear please stay on your preventative treatments they work.

[00:28:10] Yes, I beg everybody, please stay on them don't come off.

[00:28:15] **Landy Thomas:** Honestly, it's something that takes saying sometimes is that it provides you a sense of safety. Preventative treatment are smart, and they're the one way that you can really just feel stable again. And to get to a point where you're not having a flare every month or, however. Gosh, I went paralyzed, my arm paralyzed, my bladder paralyzed. I'm blind my right eye, blind my left eye, blind my left eye again.

[00:28:43] **Heather Dawn Sowalla:** Right, it's terrifying. Now the treatments are getting better, and that is amazing. The next thing I really want to see is a treatment for those that aren't aquaporin-4 positive. I really want that subset of patients to have something more than what we already have, and I think once we're there...

[00:29:07] **Landy Thomas:** It's on the horizon. There's so much on the horizon. Clinical trial studies coming out. People know that we have this subset that desperately needs help. And I don't think that they're ever going to be, they're never going to be left behind in any sense. I do think they are fully considered and fully.

[00:29:30] Yeah, there's just so much we still don't know, but there's so much that we have learned. And you and I could see that because we've been in the ER for quite a while, we've seen it when it was the worst. I mean, my ER doctor turned me away and said that he wouldn't treat me because I was going to go paralyzed and blind anyway. So, there wasn't any point of it all. It's stuff like that. It's ridiculous.

[00:29:56] That was how it was 15 years ago. That's how it felt. Even physicians were thinking that it's no point in prolonging the inevitable. That's not the case. Especially not now. So, there's a lot of hope. I would say, just to talk about what I did to cope. As a kid, I had a really hard time wrapping my head around the idea that I could have another attack just like at any given point and lose the function that I fought really hard to regain.

[00:30:33] Something that did help me I would say is imagining the plan of what my family and I would do if something did happen. Because otherwise, I had terrible insomnia. I'd be up every night just crying and



telling myself that I was about to have another flare, that I'm going to wake up with the left eye gone again. And it was not, I mean, stress we can talk about it, but in flares, I would say correlates a lot to stress. That stressing your body out is not a good thing.

[00:31:08] But I did suddenly settle upon this idea that I would trace the route, from my house to the ER and exactly what route we take. And this is what we do, and I had responded really well to steroids. Honestly, there wasn't even I don't even think plasmapheresis was an option at first, but I think steroids worked really well for me. And I would tell myself again and again and again, this is what we're going to do if this happens.

[00:31:39] And that was the one way that I could cope with the idea of losing it. Because it doesn't feel like an if it does feel like a when. Especially when you're in those first couple years and it's just bad. Do you think there's any methods that you would say that help you to like mentally calm down when you're in a bad spot? Or do you mostly just turn to a book or talk to your therapist? What really works for you?

[00:32:08] **Heather Dawn Sowalla:** So, I would turn to a book or writing or my therapist, but I'd also do something similar to you. I would really have, like, I need to have this plan in action. Like, if this happens if (a) happens, I need to do (b). If (c) happens, I need to do (d). I used to carry around a binder with all of my medical records because, I mean, back then, especially back then, nobody knew what it was.

[00:32:35] So, I needed to be able to educate the doctors so that they knew how to treat me. And I don't know how many times I'd go in and this doctor would be clueless, and I'd be like, well, you don't know what you're doing. You need to do this and then this and then this. I mean, I got to the point where I advocated so well for myself, and then I started advocating for other people, and that was a huge thing.

[00:32:58] **Heather Dawn Sowalla:** But the other thing that I really did to calm myself down if I was really agitated is, I'd take my fingers and I would just tap on my face, just random places. I call it tap talk, and I would just tap, and it would kind of almost meditate me down into where I was a little bit calm. Or if I was really overwhelmed, I would count in my head, like, one, two, three.

[00:33:27] Eventually, I would get to a number where I'd be breathing easier, and I'd be calmer. And that really helped just kind of really mellow me out a little bit because my anxiety used to be insane, and I was put on anxiety medication because it got so bad.

[00:33:48] **Heather Dawn Sowalla:** But just all of those methods together really helped. I still like the first thing I do is go back to a book or painting or reading or writing something, because I love the arts. So, I always try to go to that place to get out of my head and it helps, but it's always in the back of your mind. No matter what, it's always there.

[00:34:12] **Landy Thomas:** I think that's totally awesome. I think that, honestly, you should have everyone should have an arsenal of different coping methods to turn to. When one doesn't work, try a different one. Especially talking to other people, especially knowing that we have this wide community for you that has been here for quite a bit. I mean, 20 years is a long time to be here supporting people and taking care of those who are new to it or those who are in a pinch.

[00:34:50] It's good to have people and I can't stress that enough and the possibility of always having someone to turn to when it gets bad. Just knowing people aren't there can sometimes just be enough to get you through a really dark day. What advice would you give to someone who's been recently diagnosed with this disorder?



[00:35:13] **Heather Dawn Sowalla:** The first thing I normally tell patients is that it's okay to cry. If you need it, go outside, scream. Just yell your head off. I think really that release really helps. But then once you're done taking that time to be sad or be upset, I need you to come back to the community. Don't ever stay away. You need to come back because your fight is not done yet.

[00:35:43] We're here as a community together to lean on one another and being able to lean on each other helps us get through. Even if we have family or a good support system, they'll never totally understand what others in the community do understand, and being able to talk to them really helps.

[00:36:06] **Heather Dawn Sowalla:** The other thing I always tell people is stay off of WebMD or any of those sites. Don't read it because half of the information is either dated or just wrong. Go to the different foundations. Go to SRNA. Go to Guthy. Go to Sumaira. Any of those foundations are going to have the legit information. The stuff that is true is tested, has science to back it up.

[00:36:37] If you're able, read the science journal articles because that's where you're going to get the most information. I mean, sometimes it's hard for people to go in and understand what they're reading, especially if they're new. When I first started reading all of these journal articles, I would sit there with my medical dictionary.

[00:36:57] **Landy Thomas:** Yeah, you have to.

[00:36:58] **Heather Dawn Sowalla:** And my article, and that's the only way I was able to get through it. And now I don't even need the dictionary. I memorized all the important stuff. I know it all, so I can read it but that's what 20-plus years of NMO does. It turns you into a not a doctor, but you might as well be a doctor because you know everything. I'm like a walking encyclopedia, and I really like to help other patients because I have all of that knowledge burned into my brain.

[00:37:28] **Landy Thomas:** Right, I mean, you pick it up as you go a lot of this stuff. I mean, when you first approach a research article, if you didn't know anything about it or you didn't know anything about the disorders, it does look like a lot of big words, but you just break it down. It takes a while.

[00:37:43] **Landy Thomas:** I mean, my mom is so fast at it. I'm still really good at it. I'm still fast at it because, of course, I've grown up with it. I've grown up alongside it but, honestly, it just takes a lot of time and a lot of but sometimes reading those articles can bring you comfort and peace, especially when you can figure out what's going on with research, what's going on with disorders and trials, and then being able to see what's happening and understand it for yourself is important.

[00:38:14] Although there's so much great information disseminated through the organizations. That's a little bit more, that's a lot less jargon heavy. It's nice to see the medical research too just for itself because it's a good sign. Honestly, I think and there's more and more research coming out year by year, and it's great because, I mean, when I was a kid when you look up the word Devic's disease, because that's what it was called. You would see seven articles, and that would be it. And none of those were really good. And one of those was information about the death rate, and that scared my mom to her bones.

[00:38:55] **Heather Dawn Sowalla:** Definitely.

[00:38:56] **Landy Thomas:** It haunted her for years, and she just would cry. It's not an article that's at all true, especially not anymore. That kind of stuff. It is nice to have so much information that is being generated

and then being spread out. Honestly, I think it's a great sign that these research articles are coming out. I definitely second Heather in saying read them for yourself. Learn how to read them. Become an advocate for yourself. If you need help, there are so many great organizations and so many great people that have the best of intentions for you and want you to have a wonderful life even with the circumstances being as they are. I would like to ask if you ever talked to your doctor about your concerns about relapse. Do you ever like to talk to him about it? Do you have discussions about alternate treatments or stuff like that? Or do you kind of research it for yourself?

[00:40:16] **Heather Dawn Sowalla:** I do a little bit of both. I am blessed to have a really amazing team. I have an amazing PCP that I can call at 3:00 AM. I can have him paged and he'll answer. Not many doctors like that exist anymore. So, I can call him and if I need something, he'll meet me at the hospital or tell me what I need to do or go here or go there, and that's amazing. He'll even do house calls, and you never see that anymore.

[00:40:48] **Landy Thomas:** No.

[00:40:50] **Heather Dawn Sowalla:** I'm in a small community, so, I mean, it's easier to be done here. Then I have my neurologist who is amazing. I met him by chance. I was in the hospital. I had a flare, and this doctor was on call. And he came into my room because he was there for the day, and he was going to treat me. He knew what NMO was and I'm like, oh my god. You understand. You know what this is. Tell me what you know because I want to know what you know to see if that's what I know.

[00:41:23] I mean, he sat there with me for probably an hour in my hospital room, literally going through everything he knew just offhand. And it's like I looked at him, and I was like, will you be my neurologist? Yes, I'll be your neurologist. And from that point on it's like, I no longer had to worry about if the doctor is going to understand or if that doctor is going to say, it's all in your head because I had a doctor or five do that.

[00:41:53] So, being able to have him and then I can talk to him about anything. From treatment options, if I don't like what's going on or if I see this new treatment coming up the line, what does he think about it? I'm comfortable enough to talk about bladder, bowel, and sexual dysfunction and he's a man. So, I didn't think that that would be something I'd be comfortable with, but I really am and he's young.

[00:42:22] One of the other first things I asked him was, are you going to leave the area? Because a lot of the doctors would come into these small areas, and then they'd leave. And he's like, no, my family is from here. My kids are here. We're staying here in the small community. And I knew at that point, it's like, well, you and I we're a perfect fit. I really feel comfortable we can talk about anything.

[00:42:46] **Landy Thomas:** Good.

[00:42:46] **Heather Dawn Sowalla:** And then he's another doctor if I call him, he'll FaceTime me at nine o'clock at night to check in, and I like that because I have that connection. Whereas I don't want to put the large research facilities down, but I don't know if you're going to have that with those doctors just because they're so busy. I like having that personable doctor and, I mean, that really helps.

[00:43:16] **Landy Thomas:** No, that's totally fair. That's amazing that you've got this great team. To those listening, please assemble a good team for yourself if you can. I know some people live in more rural areas, and they might not have the best access to care. If you could go to see someone that at least knows what NMO is, it does change a lot.

[00:43:38] I mean, I'm seeing somebody now and she didn't know what NMO was. Now I have to go and talk to her about some stuff that she ordered the wrong type of blood work. She didn't order my levels right. So, it's things like that. If they don't know what NMO is, sometimes you have to hold their hand a bit more. I mean, make the choice that you have to make.

[00:44:02] If you're going to a doctor that doesn't know about NMO, be prepared to have to educate them of that or at least direct them towards the resources that they need to see in order to understand the conditions. But if you can't get fortunate enough to find a doctor that knows what NMO is and might even know more than you, shockingly enough, then go with that person because those people are you and far between.

[00:44:26] **Landy Thomas:** As time has gone on, more and more people know about NMO which is great. And more and more doctors actually can at least understand what the word is and not just like, how do you spell that at you? But at the very least, definitely, just be prepared. If they don't know what NMO is, you're the one that has to get them up to speed because otherwise, you will have miscommunications or just things that are off.

[00:44:52] Definitely, it's great and awesome to hear that you have got that team. I'm so happy that you are managing things so well even though you do live in a smaller area where resources can either be limited or you might have to drive a long time to get to a really good neurologist.

[00:45:12] **Heather Dawn Sowalla:** Definitely.

[00:45:14] **Landy Thomas:** Well, that's about it. Is there anything else you'd like the chance to say before we wrap things up? Any final notes or regards?

[00:45:24] **Heather Dawn Sowalla:** The one thing, just to kind of jump off of what you just said. I also want patients to know, that if you're listening, it's okay if you're not comfortable with your neurologist to fire them. You're allowed to go to a different doctor if you don't feel your doctor is doing a good enough job or that you don't feel comfortable. There's always another neurologist out there. Even if you have to drive a little bit, it's okay.

[00:45:53] It's totally acceptable. I see a lot of patients feel like they're going to the big hospitals, or they have this clinician that's supposed to be so awesome, but they don't connect with them, or they don't feel comfortable. It's okay to feel that way. I was like that. I went to one of the top doctors in my state, and we did not mesh, and I fired him. And then I found the neurologist that I do, and it was a good connection. So, that's just something I want patients to know. It's totally acceptable if you're not comfortable. You can seek a different neurologist.

[00:46:31] In the Guthy Jackson, we do have a list of doctors, and we have them from around the world, different states, different cities. And these doctors have all been verified that they treat NMO, and they know NMO, and that resource is available to you if you need it. So, that's one thing. And then the other thing, I just want to thank you for having me. It's really great to connect with you. And as much as you look up to me, I look up to you because you've also been a warrior for so long, and you're inspiring to many.

[00:47:07] **Landy Thomas:** That's very sweet. I appreciate that. I mean, I've always seen you and I've appreciated some of the posts that you've made and I'm like, it's hard for me because to reach out. I don't know because I was just a little kid at the time, and it's like, I've known that these people are there, but sometimes they feel like they're older than me or wiser than me.

[00:47:33] But the idea of having people meant a lot, and people like you and people like Grace really made me feel safe. So, it meant a lot and I'm so just grateful that you said yes because like you were one of my first person that came to my mind was like, you don't get to have a voice nearly enough because you're so brilliant. I like it. So, thank you. Thank you for being on.

[00:48:04] **Heather Dawn Sowalla:** Thanks. I really appreciated being here.

[00:48:10] **Announcer 1:** Thank you to our "ABCs of NMOSD" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

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