

NMOSD Stories:

Ireland

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Intro: [00:00:00] ABCs of NMOSD is an 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: [00:00:57] Hello, and welcome to the ABCs of NMOSD podcast series. Today's podcast is entitled "NMOSD Stories: Ireland." 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. 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.

[00:01:23] 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.

[00:01:35] For today's podcast, I was joined by Ireland, someone who was diagnosed with NMOSD.

[00:01:41] Thank you so much for joining us today. Do you mind just introducing yourself at first?

Ireland Thomas: [00:01:48] My name is Ireland Thomas. I am 18 years old and I just received my associate's degree.

GG deFiebre: [00:01:53] Nice. And, at what age did you start experiencing symptoms of NMO?

Ireland Thomas: [00:01:59] I started experiencing notable symptoms at around six years old. And we had a few strange incidents when I was around four, but we're not exactly sure if that's tied in or not.

GG deFiebre: [00:02:10] Okay. And then what were these initial symptoms? If you could just talk a little bit about, you know, I know it might be hard for you to remember kind of exactly what was happening, but from what you remember from, you know, what your family tells you, before these initial symptoms and kind of what, what happened at the beginning?

Ireland Thomas: [00:02:27] For my attack when I was turned six years old, I can very vividly recall it. I was in terrible pain in my back. I couldn't sleep at night at all. It felt as though acid was being poured on my back, no matter what position I was in or how I was laying down. It was just like fire all the time. Throughout the entire night, I'd go without any sleep, that sort of thing. And I would just vomit all night long from the pain, or

maybe because a certain lesion was on a certain part of my spine that made, made me vomit. But it was a very, very frustrating time. I was also experiencing around, around that time, weakness in my legs, and the onset of neuropathy in my legs.

[00:03:05] I have issues walking around for very long distances. It's gotten better throughout the years, but back then, I could barely even walk for over 15 minutes without having to sit down because it feels like there's like, like I'm walking on knives or on fire. It's pretty terrible, but it has improved over the years.

GG deFiebre: [00:03:24] Got it. And so when you were first diagnosed or when you, you know, when you first started experiencing these symptoms, when you said you were, you were six, what happened? Did you go, did you go to an emergency room? Did you, did you go to your pediatrician or a primary care doctor? You know, what kind of happened when you started experiencing these symptoms?

Ireland Thomas: [00:03:41] We did go to our pediatrician quite a few times. I had a couple attacks throughout, when I was, first got it and when I actually got diagnosed. The problem was, just because information was so scarce back then about it, my pediatrician really didn't know what to do about it. She referred us to a GI doc because she got really caught up in the details of me vomiting rather than the pain that was so terrible. We went to the emergency room quite a couple of times, but it was just a difficult situation, honestly, because nobody understands.

[00:04:12] It was hard to articulate what I was feeling because I was, you know, six and seven and eight. I really couldn't explain what it was fully, other than I was just in the most terrible agony I'd ever felt.

GG deFiebre: [00:04:24] Right. Yeah. No, it's, you know, as a, as a kid, it, it must be difficult to kind of explain your, your symptoms and how you're feeling, you know, to, to a doctor or, you know, your family.

[00:04:35] So I know you said you had this attack when you were six. When did the, you know, the diagnosis of NMOSD kind of... do you remember when that started being discussed? Or what was the process that kind of got to there? Did you have an, an, another diagnosis at first or?

Ireland Thomas: [00:04:51] Yeah, so I finally, or not finally. I went blind. I finally went blind and that was enough, like, solid, something's really wrong here to get, get an optometrist referral. So, we went to the optometrist and they were able to see that my optic nerve was, had severe damage. And then that led them to think that maybe something more was going on.

[00:05:14] They leaned, they leaned towards either a brain tumor or ADEM. And then I started going to a neurologist to see what was up with that. And then they started to lean more towards MS. But then my optometrist who we, who was really knowledgeable about NMO actually, suggested that I might have NMO and, or NMOSD now, but it was called NMO then. So sorry if I keep slipping up. But he suggested that we turn in blood work. So we went to our neurologist, and he turned in my blood work to Mayo Clinic and they were able to confirm that I had NMO. And I was positive for the not MOG, but the other one.

GG deFiebre: [00:05:51] The aquaporin four antibody.

Ireland Thomas: [00:05:53] Yep.

GG deFiebre: [00:05:54] And so how old were you when you experienced this, you know, sudden bout of blindness and, and then eventually the aquaporin four positive diagnosis?

Ireland Thomas: [00:06:05] Yeah, I was eight years old. And I went blind in my right eye, and we did not, we weren't able to catch it in time. So it's permanently gone, kind of. I have a little bit peripheral, and after the treatments or whatever we went through, when we did steroids, I regained color, surprisingly enough, but not really. It was like gray scale, and there was a big, gray blob in the center. But now I have peripheral and color in the peripheral.

GG deFiebre: [00:06:32] Got it. And then, you know, so in between when you were, you know, that first attack, and then when you were finally diagnosed, were you on any medications? Or, how were they kind of treating you, if you remember, during that time?

Ireland Thomas: [00:06:45] Between the, between being six and being eight?

GG deFiebre: [00:06:47] Yep.

Ireland Thomas: [00:06:48] They were not treating me.

GG deFiebre: [00:06:50] Okay.

Ireland Thomas: [00:06:51] Sadly. I mean, it's, it's kind of devastating, like, as a child to not really be fully believed, but that was kind of the situation. Our pediatrician, she just didn't know. And she wasn't able to understand that this was not some sort of issue with GI. She kept thinking that it was constipation that was causing me to be so sick.

[00:07:14] And it wasn't until I went blind that we finally had, like, evidence to show that I was really sick, which was really sad, honestly. But, you know, as I've grown up, I've gotten to have so many amazing doctors, and it sucks that I didn't have the best or, you know, the person that knew right away what it was like some other people have, but it's totally okay.

[00:07:37] Now that I'm an adult, I have my own great doctors, great crew of doctors behind me. And every single doctor that was with me through that journey really did support me.

GG deFiebre: [00:07:47] Yeah, no, that', that's, you know, I can't, you know, I imagine that was a super difficult time.

Ireland Thomas: [00:07:51] Yeah.

GG deFiebre: [00:07:52] But you know, I, you know...

Ireland Thomas: [00:07:53] It's been a long time, but it is hard.

GG deFiebre: [00:07:56] Yeah. Yeah. And so, you know, when you got this diagnosis of NMO, you know, especially as a, you know, a fairly young kid, you know, did your physician explain to you what it was or did your, your family? Or how, how did that kind of experience go for you in terms of understanding what NMOSD is?

Ireland Thomas: [00:08:18] I distinctly remember just, my, my doctor didn't tell me right away. He told my parents. And I went out in the hallway, and then my mom comes out of the room, and she's just crying really bad. And it was just really heartbreaking to see that. I didn't understand really, fully what it was. I knew that something was wrong. But it wasn't until a couple of years later when I was watching an episode of ER on NMO that Grace, I forgot her last name, but she's Grace.

[00:08:45] She's a very prominent member of the NMOSD community. She did a special on that show. And it wasn't until I watched that show that I realized that I could die from NMO, which is really, like, emotionally impactful, I think. Like, I didn't understand it. I didn't understand that death was even an option, that sort of thing.

[00:09:04] I just thought, oh, I might go blind someday, or I might be paralyzed a little bit, but not that, the, potential stuff of it. And my mother was told by our neurologist, and this is an outdated fact maybe, that 30% of people who had NMO or NMOSD died within the first five years.

[00:09:23] That might be true. That might be, not be, not be true, but that was kind of her working definition of it. So she kind of explained that to me during that, after I'd seen that episode and after I started crying so bad.

GG deFiebre: [00:09:35] Oh, yeah, no, that must've been incredibly difficult as a, as a kid to, to hear. And kind of, you know, it's hard for anyone to kind of grapple with that sort of thing. But, you know, as, as a child, it's, I, you know, must have been, you know, incredibly difficult as well. So thank you so much for sharing your...

Ireland Thomas: [00:09:54] Yeah, like, emotional and crying-ish, but I just want to tell my story pretty genuinely.

GG deFiebre: [00:09:59] Yeah, no, no, I, you know, we, we really appreciate that. So, you know, when you, so when you had this, this attack and you had this, this diagnosis now, did you receive any acute treatments at the time? Did like, did they give you any steroids or plasma exchange or IVIG? And, you know, how did your physician explain to you kind of these different options, if they did at all?

Ireland Thomas: [00:10:22] They did steroids, and they did IVIG. The steroids, like they explained to me what might happen, that sort of thing. IVIG was more just like, oh, this is going to help you, your body feel good. Like, it's going to be okay. But, steroids definitely was a difficult conversation just because of the weight gain that I had to deal with after that.

[00:10:43] I really ruined my self-image for a very long time after gaining 30 pounds in a month or two months. I was very small for my age, but like, around 60 pounds, and I went from 60 to 90 and then all of a sudden, a 90 to 120, that sort of thing where it wasn't, like, even fair. And I just definitely, the steroids was a difficult conversation to have that, like, you have to be fat or, you know, like, you have to gain a lot of weight in order to survive. But then my own social identity changed a lot because of it.

[00:11:17] But I did have that, I remember having that conversation with my mom, with my dad, with my doctor, like what is going to happen? What is the side effects of steroids kind of thing.

GG deFiebre: [00:11:27] Right, right. Yeah. I know steroids are definitely known to cause you know, the steroid bloat or the chipmunk cheeks. I remember having as well when I had steroids.

Ireland Thomas: [00:11:38] For sure. Kids can be so cruel. That's the other thing.

GG deFiebre: [00:11:42] Yeah.

Ireland Thomas: [00:11:42] Just because I did have to go back to elementary school after I was done with all my hospital visits for that year. You know, after the main hospital visit ended, and I still had to go back to school, it was just such a nightmare for that.

GG deFiebre: [00:11:55] Yeah. And so did you, did you spend time in like a rehabilitation hospital or were you just in the hospital, you know, after this diagnosis? What, what ha-, you know, if you could just talk a little bit about your experience kind of just immediately after your diagnosis and...

Ireland Thomas: [00:12:08] Just, like, rehabilitation, or just recovery?

GG deFiebre: [00:12:12] Yeah. If you went to a rehab, you know, some people go to a rehab hospital, some people don't, you know, depends on your symptoms.

Ireland Thomas: [00:12:18] Yeah. I did a little bit of rehabilitation. After I turned eight, I still had a few more attacks afterward. Because, though my doctor was able to diagnose me with NMO, he still didn't know NMO. Like he didn't really know it. So he didn't know that NMO had a lot to do with spinal cord lesions and brain lesions, that sort of stuff. He was mainly focused on the optic neuritis. So I did actually deal with a transverse myelitis attack afterward and even after I'd gotten a diagnosis, but that just goes to show... It wasn't really his fault.

[00:12:51] It was just no information out there. I mean, literally you could search the word NMO, or you couldn't really search NMOSD because it didn't exist yet. But you could search the word NMO and there would be like eight pages, and that would be it. So that was really difficult for him, for sure.

[00:13:06] He didn't really fully grasp that the situation was so much bigger than he had expected. So I did have multiple other attacks afterward from which I had to do rehabilitation and recovery from those. So I did, I have another optic neuritis attack in my left eye. That one we did catch because it was, you know, within our, we were able to go to the hospital and get steroids within 24 hours, and I got full restoration in that eye.

[00:13:31] I also had just transverse myelitis attack, where I started to go paralyzed. I was dragging my leg a little bit, and I had lost use of my bladder. And then from that, I did get most recovery. I still have trouble peeing. It does take me longer to pee for sure.

[00:13:48] But other than that, it has been a mostly full recovery. But that, and I also had a, an attack in my arm that caused me to have, I needed physical therapy for the arm, for sure. All of a sudden, I was losing my ability to use it. So I did, I was able to go on steroids and fix most of those problems except for the bladder issue. But that did require physical therapy to mend for sure.

GG deFiebre: [00:14:12] Got it. And so did they, you know, so you said you had these multiple attacks after the one when you were eight. Did they talk at all about putting you on any long-term treatments, long-term preventative treatments? Or is that, are you currently on any or...?

Ireland Thomas: [00:14:25] Well, like, long-term, like, like Rituxan, yeah?

GG deFiebre: [00:14:27] Yep, yep.

Ireland Thomas: [00:14:28] Yeah, so I am on Rituxan. And I've done pretty good on it. After, after we figured everything out, and we insisted that, yes, this is in fact related to NMO. And we went back to our optometrist who recommended that we go straight to the ER. We were able to start a treatment of Rituxan, and that has worked really well for me, for sure.

[00:14:46] I haven't had to switch off of anything else. I think it's like, it's pretty perfect, other than the fact that it did lower my immune system incredibly low. I went straight to nothing, and I had to go on IVIG and then

subcutaneous IgG to boost my IgG levels back to basically normal. Because I, I started getting pneumonia for six months straight and 14 different cases of pink eye that I would treat with antibiotic eyedrops, but it would still never go away, really.

GG deFiebre: [00:15:16] Got it. And how long have you been on the Rituxan for?

Ireland Thomas: [00:15:19] It's really hard to tell for sure. So I would say 10 years, but they told me not to do it for 10 years back then, but it's been perfectly fine for me all that time, other than the odd, other than the loss of IgG. But I think I've done it, like, 26 treatments of it because we started off that first year doing it every three months instead of every six, but then we've been doing it every six since then.

GG deFiebre: [00:15:43] Okay. And then, do you find that the Rituxan has kind of reduced the number of relapses you've had, or...?

Ireland Thomas: [00:15:51] For sure. It's, it's gotten me as close to remission as possible for, for, for my illness, for sure. I live a mostly normal life other than the, you know, the fear and that sort of stuff, but I do live a mostly normal life now.

[00:16:09] It's very cool to see that. I mean, like, it's been six years since I've had an actual notable attack or a, a pseudo flare that seemed really terrible. So that's been really cool actually to see.

GG deFiebre: [00:16:21] Great. Yeah, no, that's really good. And then, so we talked a little bit about some of the residual symptoms you experienced.

[00:16:27] I know you said, you said still have some bladder issues, you know, obviously some visual issues. Do you have any other residual symptoms you have? And if you do, how do you manage them?

Ireland Thomas: [00:16:37] Neuropathy in my feet from... I still feel a little bit like walking on knives or like on fire a little bit. I have some weird knee pain that comes every so often.

[00:16:47] It feels like just the most ridiculous arthritis in the world. I feel like I'm 80 years old or something. But it is something that's been there ever since, for, I mean, at least for six years. But then, other than that, I would say, like most people, I do suffer a lot of fatigue. Just, I have, I consider myself a spoonie, which is a term where it's like, you only have a certain amount of energy to expend each day.

[00:17:14] And some days you have more energy and some days you have less. I tend to have a medium amount of energy, but sometimes I just am so, fatigued for some reason that I just, I just can't. It's very frustrating, especially if I plan something in advance and then all of a sudden, I'm really tired.

GG deFiebre: [00:17:30] Right. Yeah. No, those bouts of fatigue can be pretty difficult to deal, for sure. You just feel like you have to take a nap and, and, or just not do anything. And then, what is the most, you know, I'm going to kind of frame this as a two-part question. So what is the most difficult part of living with NMOSD? Do you have any fears about it? And then kind of on the flip side, what are you hopeful for, you know, as someone living with NMOSD?

Ireland Thomas: [00:17:57] Yeah. I would say like, for me, just because I am doing very well after, you know, six years roughly of, of kind of remission, it's been, there's a lot of big fears, you know. You don't want to ever deal with that again. You don't want to get sick again.

[00:18:16] Or, sometimes when it's like at the five-and-a-half-month mark before I'm able to do Rituxan, then I just get so freaked out that I could even be starting my own flare, because it does tie a lot in with anxiety and that sort of thing. The more anxious you are, I truly believe that you can actually start triggering a flare in yourself.

[00:18:35] I believe that science supports that conclusion, but definitely when, when it gets so close like that, when it's like five-and-a-half-month mark, I kind of just get so terrified that I'm going to go paralyzed or blind or the, you know, the life that I've just began to build, like just will be taken from me again.

[00:18:53] And it's definitely interesting to, to know that you've been doing so good, but like be so afraid all the time that it's just going to be taken from you. But the flip side of that, the hope is that I have a really good story, you know, like I have dealt with so much of this terrible illness that a lot of us have.

[00:19:16] It's just so, so life-stealing, you know. You, you spend all your time thinking about it. But like, I've succeeded in, in conquering it as much as I can, kind of the, it's, you know, NMOSD, it doesn't have a cure. It doesn't have a conclusion, really. You kind of just live with it. But it, I feel like of all the stories I've heard about NMOSD, I've been one of the luckiest people in the world, the luckiest unlucky person. Like, as a kid, I remember being told that NMOSD in children was like one in 10 million.

[00:19:51] Of course, I think the numbers have risen since then. But like, it's just ridiculous to think that I've been so unlucky to be chosen, to be, to have NMOSD, but I've been so lucky to, to not be completely paralyzed forever or completely blind forever. I just feel like, my heart just really stretches out towards those who are suffering even worse than I am.

[00:20:12] And I, I feel so hard for you guys. I'm so sorry that you have to deal with it. And I really hope that your stories can end like mine, where things get better. You know, because they do get better. And I hope that you guys have the recovery, however slow, because I can guarantee you that after 10 years of dealing with it, things have gotten better slowly over time.

[00:20:37] But things that I couldn't catch have gotten slowly better. My eye, that it went so completely dark is, it's not better yet, but it is gray instead of black. And that's like such an amazing thing to me. Like, it has gotten better over time and it's so slow, but I hope that you guys get to witness some of that for yourselves, just to be able to see progress, however slow, is happening.

GG deFiebre: [00:21:04] Yeah. No, for sure. And I, you know, I think, I think, you know what you're saying too, you know, it's important. What I feel like what you've shown that you've done too, is kind of balancing, you know, being really grateful for what you have and your current situation, and also being hopeful for the future, you know, no matter what, you know, no matter how difficult it is currently, or, you know, whatever, you know, and adapting and learning how to adapt and, you know, dealing with these challenges can be, you know, incredibly difficult. But, you know, you obviously have, have shown that you've, you know, you've done a really amazing job dealing with them, you know, especially as a, being diagnosed as a kid, I feel like, you know, as you said, NMO is far less common in children. So yeah.

Ireland Thomas: [00:21:53] I know the numbers are so much different now because, you know, we actually have more information, but that's what my doctor told me way back then. Yeah. NMOSD now of course.

GG deFiebre: [00:22:03] Right, right. And then, is there anything you wish medical professionals would know about treating someone with NMOSD? And so, you know, this might be kind of, when you were first diagnosed, you know, as a, as a kid, your experience with that, and then maybe now as well.

Ireland Thomas: [00:22:19] Well I think as time has gone on, information has gotten, gotten so much better. I go to doctors now, like, that aren't even related to NMO as much. Like, like my optometrist wasn't even related to NMO back then. Somehow, he knew about NMO, even though nobody else did not.

[00:22:36] Not even my neurologist knew that. But now I go to my, like, my GI doc or any, any doctor that's not even related to the field, and they'll know instantly what NMO is. It's very shocking. I, especially my allergist, I was shocked when my allergist knew what NMO was, like, or NMOSD now. It's just so cool to see that information has gotten so much better on it.

[00:22:56] And I, I'm really proud that organizations like SRNA and other organizations, of course, have made this information more widely available so that doctors actually know what they're dealing with a little bit better, so that there's no more stories like mine where people didn't know. I'm, I'm really proud of that.

[00:23:14] I'm so happy for you guys, that you guys are having more of a voice every single day. And I, I definitely love that so much about your organization. But other than that, I would say that doctors still need to know that the symptoms of NMOSD can be very, very wide. It's not as simple as it seems for sure.

[00:23:33] It doesn't really matter where the lesions, or, it doesn't matter what the main symptoms are. Even if the lesion is somewhere really strange, it can have a very strange effect on the person, for sure. So I have brain lesions. I have spinal cord lesions. I have optic nerve issues, of course. But just depending on where that, where that lesion is, it can really affect different things.

[00:23:55] Like for me as a kid, I know that because my lesion was in a certain spot that makes you vomit, it was making me vomit. Like it wasn't a GI issue. It was because that lesion was right there where, where, where it makes you vomit. So certain things that don't seem like NMO can be NMO actually.

[00:24:14] And it's better to just keep everything available, or like, don't like mark off a diagnosis because it doesn't fit the, doesn't fit the definition perfectly. Just still keep it in your view. I, that's so hard to say. Obviously, I'm not a doctor. I don't know everything. But I can guarantee you that some of these cases are so difficult to name mainly because they don't fit the perfect definition of NMO or MS or whatever illness that people are dealing with. Because especially with things that affect the brain and the spinal cord, it can just vary so much depending on where that lesion is.

[00:24:49] And it's kind of interesting to say the least because you, everybody is a mix of different symptoms for now, but that's why it's a spectrum disorder now when, when it used to be not, you know. NMO had its certain definition and NMOSD doesn't have that as much. Like you can, you can have those symptoms still. Just the strangest things can be a part of that, that illness, for sure.

[00:25:13] Just to keep an open mind on everything, just in case. And not to say that you have to or anything, but that's just my best advice, for sure.

GG deFiebre: [00:25:21] Got it. And then, is there anything you wish your friends and family knew about NMO?

Ireland Thomas: [00:25:26] I think there is such a toll that NMO takes on the, on the social aspect of living. It's hard to fully, like, it's hard to explain NMO, of course. But it's also hard to rejoin society when you've been cut off from it. And that's true for young people. That's true for old people. That's true for everybody. That once you have that issue, it's so hard, especially with a weird, rare name that nobody's heard of.

[00:25:56] Like, if you say you have cancer or something like that, people understand a little bit better, but like, with NMOSD or something that's not, you can't recover from and you can't treat away necessarily, then it's hard to rejoin society that way. You feel separate from other people, so you become separate from other people. And, people don't know how to react to you, so you don't rely on other people in your times of need.

[00:26:20] So it was really hard for me, especially as a kid, growing up with friends that couldn't understand and friends that just seemed so shallow to me when I was, like, so wrapped up and in the misery of NMO that, that it brings. Just that, friends and family, it's so hard to react properly to an NMO diagnosis or NMOSD diagnosis. And, just to commiserate with people, that's the most interesting and cool thing I've ever been exposed to is just, sitting down and saying, "Hey, I understand what you're dealing with. I, or I don't understand what you're dealing with even. And I'm just going to sit here with you and we can just cry it out."

[00:27:05] Like, there's no way that other people can fix what's wrong with me. There's no way that people can solve every problem yet. But it's good to know that somebody can sit next to me and just understand that something's wrong, and that even if they don't understand the full details of whatever you're dealing with, it's good to have a person that is taught to know how to sit down and sit in the pain with you.

GG deFiebre: [00:27:33] Right. And then, you know, how do you explain NMOSD to others? So your friends, your family, you know, strangers, I know sometimes strangers have intrusive questions sometimes. How do you go about explaining NMO to others?

Ireland Thomas: [00:27:49] Well, for NMOSD, if for, for people who aren't going to have much knowledge on, on that forefront, I tend to use Dr. Greenberg, who is kind of a prominent figure in the NMOSD, just neuro, in neuroimmune society, basically. He uses a really great definition for, or like a great story, kind of to tell how he, to tell how this works.

[00:28:13] So he says that there's like a cat inside of you that's like pulling on different wires. Like you're like a bass speaker or something. And then by pulling on different wires, certain things aren't connected as well, or aren't connected at all. And, just that, by pulling these wires, the sound that comes out of the bass speaker might be a little bit different.

[00:28:31] So for me, that made a lot of sense when I was dealing with, or a similar story like that, made a lot of sense when I was dealing with my blindness in my right eye, just to kind of explain how the optic nerves work, because optic nerves is kind of like a weird thing. Like, there's this weird little wire that's coming out of the back of my eyes? But that's kind of, was a good explanation for me as a young person who has NMO or NMOSD, and for other people, other people's children who don't really understand that sort of thing, or even people that just don't have the time to understand it, like, you can just kind of give them a quick definition like that. So I really liked using that.

[00:29:10] But, other definitions that I tend to use is I, I tend to explain what myelin is, like the outer coating of nerves, and that like a, a little enemy creature came into my body one day and ate a little bit of that myelin. And then all of a sudden, my body learned to attack it. But instead of attacking it, it started attacking the myelin because it kind of disguised itself as myelin. So now my body attacks itself for some reason.

GG deFiebre: [00:29:35] I think that's a really good explanation to a very complex thing.

Ireland Thomas: [00:29:39] Yeah. Well, it's easier to do that for most people than obviously with like close family members, they kind of are in the situation already, so they, they know it. For strangers, like, if people are going to come up to you and, you know, tell you what to do... that's what I've had to deal with a lot, where people are like, "you need to stand up or you, you can't be sitting right now. You shouldn't be doing that." Because I have to sit sometimes because my pain is bad. Just like, just tell them straight up. Like, no, I, I don't need to do that. And you don't have to explain yourself to people.

[00:30:12] People, other than obviously like people that are over you and like, if it's just a stranger, that's not over you in any way, you don't have to constantly explain yourself to people just because you have a, a somewhat invisible disability or anything like that, if you do have an invisible disability. And if you have a visible disability, they shouldn't be doing that at all.

[00:30:31] So, for sure. Just, make, you, you know, you treat strangers respectfully, but nobody needs to tell you what you can or cannot do, that sort of thing. So that's always been frustrating for me, especially when I was a little kid and every adult had a power over me in, in that way and thought that they could dictate what I, what I can and cannot do or what, what my boundaries are and that sort of stuff.

[00:30:55] It was hard to deal with. But for sure, it's gotten better throughout the years. And I try to let people in quickly to know what my situation is, so that they don't constantly make that mistake of, "you need to sit down, you need to do this," when I need to be able to set my own limits for sure.

GG deFiebre: [00:31:11] Got it. And then I just have one question, about kind of the, how the transition went from, you know, since you were diagnosed as a, as a kid and like, I'm sure your parents had, you know, that they were a very big part of your treatment and everything. And then kind of the transition into adulthood, how that has gone in terms of your medical care. Because, you know, I think it's important for other kids, you know, other people who were diagnosed when they were children to hear about that transition and kind of how to, and taking over, you know, working with doctors themselves and, and that sort of thing.

Ireland Thomas: [00:31:46] For sure. I'm kind of right at the cusp of adulthood, myself. So there's, this has been a mostly recent transition. I do order my own IgG medication, which is just an over the phone sort of quick call for them to, to send my shipment over. I don't tend, I tend to talk during the appointments. You kind of have to train yourself beforehand. And if you're kind of anxious like me, sometimes it's better to have like a little script to follow.

[00:32:12] Like, this is the three things I need to talk about during this appointment. This is the three things I need to get done. So for sure, even preparing yourself to do that is, is super easy to do. And it's not, it seems weird to have like a piece of paper or like your phone out during the appointment, but sometimes you just need to have that refresher, because you do have to prepare yourself to start talking during the appointments, especially if your parents are older, that sort of thing.

[00:32:37] And I, I know I'm not going to live with my parents forever, for sure. But just having them during that appointment the first couple of times that I began to talk fully was a good motivation for me to continue to be able to discuss what I do and do not need, that sort of thing.

GG deFiebre: [00:32:52] Yeah, no, I think that's, that's great advice. And especially, you know, writing stuff down on the phone, I think. You know, I try to do that too, and make sure that I don't forget anything.

Ireland Thomas: [00:33:00] It feels rude to leave your phone out [during the appointment]. But honestly, I think most doctors understand that you're just trying to collect your thoughts in a certain way. You're, you're not

like reading from a script to get something specific, like, that's, that's wrong for you or something like that. You just really want to get the best care that you can.

GG deFiebre: [00:33:16] Right, exactly. And then, is there anything else you want to talk about that, you know, I didn't ask about, or that you want to mention?

Ireland Thomas: [00:33:23] Just to further, further hit down on that point of social identity. Honestly, like if anybody in this community is struggling with social identity, I totally understand that. After having such an issue so young, I really struggled to find my own identity. Like how, who am I compared to who is the illness?

[00:33:43] Just, that's really entangled. So regardless of age, I think people get entangled with their illness a lot, and I don't think that's wrong necessarily or anything like that. But, just to, to continue to say that it's so hard to find a good community that will support you through this, but just that, you, you need to find it, for sure.

[00:34:02] You can't just stay alone, even though it's so hard to let people back in or trust certain people or just deal with it. Because, NMO does come, or NMOSD does come with so much trauma for people, for sure. It takes years and years to recover. And even if you recover from the illness, there is such a mental, mental trauma that's on people. I mean, I've experienced it my whole life, just to, to like, how do you teach yourself to live when you've been told you're going to die? How do you teach yourself to create a life when you're afraid it's going to be ripped away? Just to, like, just focus on finding community, finding people that you can trust. And just focus on yourself and making sure that you're okay, because it's so hard to, to just keep on going when you know that you're not okay.

[00:34:52] So just to, just be open with people and let them know, like, this is what I'm dealing with. Just find some way, some outlet to let all that negative emotion and pain out of you, because it is such a terrible burden for people in this community, and in, in many communities like ours.

GG deFiebre: [00:35:10] Yeah. I think, I think what you said about finding community is incredibly important. And of course, it's, it's more difficult even when you have a, you know, a rare condition where there's only a certain number of people in the world, but, you know, you can find community, you know, even with people, you know, without your condition or with something similar. Yeah. So I think I, yeah, I, I really appreciate your thoughts around, you know, the idea of finding community and how important that is for us. You know, you've got some, some tough, tough things, so.

Ireland Thomas: [00:35:41] It's, it's really lonely to just have an issue that nobody else understands fully. And it's, it's hard. Like my parents kind of understand, but they kind of don't. So it's hard to, it's hard to navigate that as well for me. I, for sure am still kind of caught up in the trauma. Like, I still live it, you know, but my parents have improved over the years. And I'm so proud of them and I'm so happy for them, but I sometimes feel so, like, embarrassed that I'm still, like, wrapped up in that pain, you know?

[00:36:12] And I think it's okay to be in pain sometimes, and it's okay to improve slowly. And I just want to, like, magnify that, like just improve as, as, as however fastly you can, you know. Like you don't have to go as, as quick as possible. You don't have to improve immediately. But just to, to improve and, and to survive, honestly.

GG deFiebre: [00:36:35] Yeah. Thank you so much for taking the time today. I really appreciate it.