

Ilona Williams

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[00:00:02] **Lydia Dubose:** Hello and welcome to the SRNA "Ask the Expert" podcast series Community Spotlight. My name is Lydia Dubose, and I moderated this podcast. 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. Our "Ask the Expert" podcast series is sponsored in part by Amgen, Alexion, AstraZeneca Rare Disease, and UCB.

[00:00:33] For this podcast, we were pleased to be joined by Ilona Williams. Ilona was originally diagnosed with transverse myelitis in 2006, followed by an MS diagnosis until in 2018, she was diagnosed with NMOSD. You can view the full bio in the podcast description. Welcome and thank you for joining us today. Would you mind just briefly introducing yourself?

[00:00:59] **Ilona Williams:** My name is Ilona. I'm 54 years old and I live in Alexandria, Virginia.

[00:01:06] **Lydia Dubose:** Awesome. And in regard to the onset of your disorder, it may have been many years ago. What age did you start experiencing symptoms? What were the initial symptoms at the very beginning of your journey?

[00:01:22] **Ilona Williams:** Well, it started, I guess when I was around 34, 35. At that time I didn't really know what was happening to me. I just was having episodes of, I wasn't feeling good, numbness and tingling, little vertigo and it was all different times where these episodes would occur and everybody, you know, one time it happened during the summer.

[00:01:53] So, everybody was like we wonder if you got West Nile virus or there were all these speculations as to what it could be because I would have the episode, I'll refer to it as episode, and then it would resolve itself and then two months later again, I was experiencing something. So, it just seemed like one thing after another, after another.

[00:02:22] **Lydia Dubose:** And then in response to those symptoms, what happened next? Did you seek medical care? Did you seek treatments? What was the response from any physicians that you worked with at that time?

[00:02:38] **Ilona Williams:** Well, it was really frustrating at first when the episodes kind of started and I was going to the doctors because it wasn't anything that was continuous or I wasn't being treated for anything. I would go to the ER. Of course, they were like, "Well you're healthy. There's nothing wrong with you." So, they would try to send me home with pain. If I said I was in pain, they kind of observed me and said, "Okay, well, we can give you this for pain, that for pain."

[00:03:07] At that time, I didn't know the difference between like neuropathic pain or neuropathy and just pain because they would, and I'd always preface and say, "Well, it's pain, but it's not like pain, like I cut myself or somebody stabbed me. It's like it's coming from inside and I don't know where it's coming from." And so, there's actually one episode where I had gone to the same ER within the same year, I think, like three times and it just so happens that the same ER doctor was there, and he had seen me previously.

[00:03:43] By the third time I was there, I heard him out in the hallway speaking and they were kind of talking about me like I was an addict. Like I was just there to get medication. When he came back in, I just lost it. I just said, "I am not here for pain medication. Yes, I'm in pain and I'm sorry I can't tell you specifically where it's coming from, and I'm just as frustrated as you are because you can't tell me where it's coming from.

[00:04:14] Please don't dope me up." Because the few times before, like the one time before that they gave me a, sorry, I'm drawing a blank, brain fog again. They gave me medication. It made me feel good while I was there. And then when I left, as soon as I got home, within a couple of hours I was right back to feeling the same way that I felt right before I went there. And so, I thought this isn't doing me any good. This is like a momentary fix. This is not helping me long term.

[00:04:54] And so, after that, I mean, I went through bouts of, I would go through these little episodes, feel bad, feel better. And I just kind of like was sucking it up. And then finally, there was one time where I wasn't feeling that great. And my husband came in and I was still in bed. He said, "Are you going to get up and go to work today?" And I said, "I can't." And he said, "What do you mean you can't?" I said, "I can't move." And he said, "Ha, ha, you can't move. Let me come over and help you." And so he kept saying, "Come on, just get out of bed."

[00:05:32] I said, "I am sitting here laying here thinking, 'I'm trying to move my legs to move over the bed' and like nothing was happening, and I'm freaking out because I'm thinking, "Why is nothing happening?" Because the night before I didn't have any issues, nothing was wrong. So, when I went to bed, I was fine and he was kind of looking at me like, "Okay, so this all happened just overnight?" And I'm like, "Yeah, well, I don't know what to tell you." So, he helps me kind of stand up and that kind of thing.

[00:06:04] And that's when we decided I need to go to, again, I went back to the ER and they were like, yeah, they did X-rays because they're like are you sure you didn't break something, sprain something and that's why you can't stand? Is it one leg? Is it your foot? And I was just like, "I don't know what to tell you." I said, "I can't stand or to walk." I said, "I can't even walk." The nurses had me on either side, and they were helping me move from like the bed. I had to go to the bathroom that kind of thing.

[00:06:38] Then they finally came back in and said you're going to have to see a neurologist. We can't find anything wrong with you. I did, I was able to, and of course, I started making calls to see a neurologist. Of course, everybody is like, yeah, we can see you in six months, nine months. And I'm like, six months? Like, I couldn't get out of bed this morning. Are you serious? So, then I ended up taking the first appointment of the first neurologist that could see me, the earliest that he could see me.

[00:07:09] And so, when I went to see him, he came out and he said, "All right, come on back but I want you to walk in front of me. I want you to walk down the hall to the exam room and I'll follow you in." And as soon as he came in, he says, "I know exactly what you have." And I was like, "Okay, wow." He hadn't even looked at me. He's like, "You have transverse myelitis. I'm pretty sure of that. We're going to have to run some other tests and blood work. So, I need to do a spinal tap," which now was lumbar puncture, but when he said spinal tap, I was like, "Oh my God."

[00:07:54] And so, we went from there and I was hospitalized for a couple of days just so he could run some tests and just get everything done, do MRIs and stuff like that. And again, it would come and go. I would have good days, I would have bad days but there were times where I was somewhat mobile and then not that easy to be mobile, get around that kind of thing. So, I went back to work and that kind of thing.

[00:08:24] And then what happened was after that, it just seemed like every episode it seemed like every couple of weeks, like every four weeks or so, every month I was experiencing something. Finally, we got -- and I was going back to the same neurologist. So, he finally said, I mean, they had me doing over-the-counter steroids. I would have these episodes and of course, people at work knew that there was something going on with me because after a while taking the steroids, I would walk in and I had the moon face they're like, oh, wow, something's going on with her.

[00:09:04] And then after I had several episodes after that, he finally said, "Okay, I think it's something more. I think you're falling more into the MS category. So, we need to do more blood work and just exams, MRIs for lesions that kind of thing." And so, they did blood work, they sent it off to NIH. And he says, "Okay, well, it does show you have," and the MRI also confirmed that I had lesions on my entire spine from I don't know all the technical, the C whatever, but like from my lower back all the way up to my brain stem. And I also had a couple of small lesions on my brain.

[00:09:51] **Lydia Dubose:** Wow. And at that point of all the testing that they were doing did they do a blood test for aquaporin-4 or for the MOG antibody at this point?

[00:10:03] **Ilona Williams:** At that time, no. It was probably around 2016. And at that time, I was shocked when he said MS because I thought I only knew of one other person that I worked with, and his wife had MS and they shared some really heart-wrenching stories about the stuff that she went through. And so, I was just like, wow, I know nothing about this. And so, I just kind of went with it. He's like this is MS and of course, at that time MS was the only, well, it was the only thing that was brought to my attention or mentioned to me.

[00:10:44] So, when I looked it up online and tried to do any research again it was terrible. I was just like, oh my gosh. And again, it varied with so many different situations and so many different people. There were so many different circumstances. So, there was no talk of like well we have to do any more tests or anything. And then what happened was I was put on a preventative medication for MS. I started on that, and I took that for a couple of years.

[00:11:15] And then after I had my, what I call my significant relapse, which was in 2018. I ended up in the hospital. And so, honestly, I don't remember much from being admitted to the hospital up until the time where I came, they said I was kind of like in a comatose state five to six weeks. I mean, I would become coherent. My mom would say she--I could tell when she would walk in because she said, "You didn't open your eyes and I would walk in, and I would put my hand on your hand. And I'd say, 'If you know I'm here or you can hear me squeeze my hand.'" And she said, "You would squeeze my hand." So, she said, "I knew you knew I was there."

[00:12:07] And then after being in the hospital, so finally, when I kind of came out of that state is when they started talking to me, and when I came out of that state I couldn't speak, I couldn't read, I couldn't write, I was paralyzed from the chest down to my toes. I had a catheter and that's when they started talking to me saying, we ran some tests and during that time that's when they figured out that I tested positive for aquaporin-4 positive. And then they start talking to me about NMO, asking me if I knew what it was. And I was like, nope, don't know any of this stuff.

[00:12:48] **Lydia Dubose:** Wow. So, quite a journey, quite a few kind of the different paths that you went on before finding the right diagnosis of NMOSD.

[00:13:03] **Ilona Williams:** And it was also difficult during that time period because between having that relapse and ending up in the hospital, I was also fighting breast cancer. So, previously I had gone through radiation. I'd gone through chemo. It was just like, wow. I told my mom when I finally could speak, "I was like this really stinks. I'm like I'm just getting punched left and right."

[00:13:30] **Lydia Dubose:** Right, you're like, "When can I catch a break in all of this?" Oh, my goodness. So, once they did identify NMOSD for you and you were hospitalized, did you receive acute treatments at that time? Do you remember kind of what that initial reaction to NMOSD was?

[00:13:51] **Ilona Williams:** Well, yes, I did. I was in the hospital just under five months. While I was there, they had me on IV steroids, they also prior to me kind of coming out of that state, they had administered one treatment to me. I don't know if I can say the names of the treatments. The treatment that they gave me, I had a reaction to it, and I was covered, my mom had pictures of it.

[00:14:22] I was covered from hives from like head to toe and they were like, "Okay." Well, they tried two treatments, and I reacted the same way to both. They were like, "Okay, this isn't working, going to have to try something else." And then I also had plasmapheresis at some point during that time. And again, I was still kind of in and out of it. So, I don't remember a lot of this.

[00:14:48] A lot of it is just documentations from speaking to the neurologist that was working with me at that time and my mom, and pictures she had, and that kind of thing. And then once I got to the point where I was coherent and able to stay awake and they started then working on me in addition to that also to physical rehab. Just learning how to sit up, how to transfer from the bed to a wheelchair, and that kind of thing.

[00:15:23] **Lydia Dubose:** And what was your experience with rehab? How long did you go through any kind of rehab therapies? And what kind of function were you able to regain over that time?

[00:15:38] **Ilona Williams:** Well, while I was in the hospital in those five months, I was very frustrated and I mean, I can fully empathize, sympathize with people in that situation because I know they were spending a lot of time with me, and they were working very hard with me. And I mean, I've gone from being a fully functional, healthy woman that worked full time, traveled, exercised, was just mobile to now all of a sudden like the big achievement was me being able to sit up in my bed by myself.

[00:16:03] And so, while I was in the hospital, they worked with me at speech therapy to get my speech back. I had to go through therapy to learn how to swallow to make sure I wasn't choking on any food, making sure I could chew it and have it go down. I then learned how to sit up in the bed and then transition from the bed to the wheelchair and then they would roll me into the rehab center. I learned how to go and stand up on the parallel bars just to stand up on my own and learn how to walk one foot in front of the other.

[00:17:02] And then I also learned, now it wasn't until so while I was in the hospital, that's pretty much how I learned to do that stuff. And then I transitioned from the parallel bars to learning how to get in my wheelchair again. And then if I needed to learn how to stand up and use a walker and then I was released from the hospital. And then once I was released from the hospital, I came home, and I had a medical bed here in my house. And then two years after that, I still went to outpatient therapy.

[00:17:36] And that's where I continued to learn how to strengthen, learn how to become a little bit more independent. I mean, like the big thing was once I got home and I had been going through therapy in and out. I remember the first time my mom, she was kind of helping me into the bathroom. I had a hospital chair in my shower, a bench. And I said to her, "I want to take my own shower," and she's like, "Ilona."

[00:18:11] And I'm like, "Mom, I'm 50-something years old," and she's like, "I'm your mother. I've seen everything. And I'm like, "I know that but still, I'm a 50-something-year-old woman. I want to be able to bathe by myself." And so, she was so worried. She would say, "Okay, fine," and close the curtain or whatever. And she said, "I'm going to sit out here on the toilet. I'm not going to help you, but I'm going to be right here if you need me." I'm like, "Okay." I mean, that was the biggest thing. They were like, what's your biggest achievement? And I'm like, "I showered by myself," and they were like, "Wow," and I'm like, "It's a huge deal."

[00:18:55] **Lydia Dubose:** So, big transitions going from hospital to home and learning how to do things again. I guess fast forward to today. What does your today look like? Do you have current symptoms that you're living with day to day? And what does that look like for you?

[00:19:14] **Ilona Williams:** It does. I am on full-time disability. I no longer work. I had spasticity pretty severely and luckily that's gotten better due to help of daily medication. And then I still have numbness in my toes all the way up my leg all through my calves, up to like my knees. That's gotten better too. So, that's also helped with my walking because they also had me -- when I got home, not only did they have me while I was using the walker, they had me in, they were like leg braces to kind of help me like help with drop foot and that kind of thing. I forget what they're called, sorry.

[00:20:04] Again brain fog and then brain fog. And so, I don't drive anymore. And so, like I do live on my own, but my mother lives close by and she's been my angel. She comes by every day. I hear her. She knocks on the door. She's like, "I'm here," and I'm like, "I know." And she'll come in and she kind of helps me with any house stuff, just laundry. I mean, she's the one who takes me grocery shopping. She makes sure I get to all my doctor's appointments.

[00:20:43] And then I do still have a little bit of what they refer to as the MS hug, which is kind of the band on your chest. And it's not as bad as it was before. I mean, before it really felt like somebody was really constricting me. Now, it's just that it's, I know it's there, but it doesn't keep me from doing anything. And so, and you get tired. I mean, that's a crappy thing.

[00:21:09] I used to joke at first, I'd say Mom, "I just need to sit down for a second." She's like, "Do you want to take a nap or something." I'm like, "No, I just need a minute to rest. I don't want to take a nap, just give me a few minutes to rest. This is terrible. I'm up and moving for 20 minutes and then I got to rest for five minutes." It's getting better.

[00:21:28] **Lydia Dubose:** It's just taking at a different pace. Well, it sounds like your mom is an amazing support and really big help in your life. Can you speak to anything else that's been a part of your support system throughout learning to live with NMOSD?

[00:21:45] **Ilona Williams:** Well, having an advocate. Well, one, I've learned how to be my own advocate, which is really good. I mean, and so, and through that, I've also kind of helped educate my mom more. So, she is also my advocate. She was always my advocate from the beginning anyway because I used to feel bad. I'm like, "Mom, I feel so bad. Like I don't want you to be here." I mean because she just retired when all

this started kicking in for me. And I'm like, "Don't you want to be out travelling and all this other stuff?" And she would say, "I'm your mother. This is what I want to do, stop telling me to go places." I'm so grateful. So, but sorry, I went off track.

[00:22:32] **Lydia Dubose:** No, that's okay. I was just asking about your support system.

[00:22:36] **Ilona Williams:** So, like I said, I try to educate myself by getting into support groups for NMO. And the nice thing now is, what I've learned when I first started this process five years back or so, it seemed to me like it was very individualized, like there would be a group here, there would be a group there. And so, at that time I didn't think that they really intermingled much, but now it's really nice because a lot of these organizations and support groups, they do kind of tie in together, they kind of mesh in one way or another.

[00:23:15] Like people from this organization or this group are familiar with this other organization or if there's something going on here, like they know what's going on there. It's almost like I wish our medical system was. I wish that all of our doctors would be cohesive and kind of working together more easily, more in tune with each other. And I do really feel like a lot of these support groups that are out there that help, teach us, and advocate for us, and teach us to be our own advocates, are like that. And I'm really grateful for that.

[00:23:50] **Lydia Dubose:** Yeah, it's awesome. We have such a good community and our community of organizations that all work together really well. And we wish everything would work well together like that. But along those lines, how did you first find out about SRNA and what drew you to want to get involved in support groups and what's that experience been like?

[00:24:20] **Ilona Williams:** Well, honestly, again, when I was diagnosed, my neurologist, he kind of handed me a book on NMO and he was like, I mean, we talked about some things, he shared some things with me, but he didn't go into like any like major detail. So, in that book, I mean, it kind of went over the, I don't know, just the everyday occurrences as far as like testing and medications, and frequency and that kind of thing.

[00:24:54] And because the one thing he did tell me when he handed me this book about NMO and we had this discussion, he said, "Whatever you do don't Google this". And I'm like, okay, so what do I do? I go home and I Google it, right? And at that time, five years ago it was nothing good like everything that was coming up I was like, "Are you serious?" Oh my gosh, I told my mom, I'm like, "I have five years. I have five good years." I mean, that was what was out there at that time.

[00:25:21] And so, things just kind of started coming up, I ended up -- at that time there wasn't much focus on NMO specifically, a lot of it was just MS and so I just started there. And then I kind of learned that NMO is not MS. And then I learned that there were more specific groups that focused on NMO, and getting involved with one group kind of led, you know, people would say, "I'm involved in this group here," or that group or whatever.

[00:26:04] And I would just kind of see things and I would just kind of reach out. At first, I felt a little bit like a stalker because I'm showing up at all these meetings. They're like, "Jeez, this lady is everywhere." But I was trying to educate myself and get as much coverage and much of a field out there as I could because I was also trying to learn if I was hearing something different or new in one area or one space than I was with another.

[00:26:31] And what I started to find luckily was after a while that they were all kind of leaning towards the same, I don't know, advocacy. I mean, methods and that kind of thing. And then I started seeing more and more of the different people of all the different groups, in all these different groups along with me. They're like, "I saw you in this group or that group or whatever."

[00:27:01] And then when I first learned of SRNA, at first, I thought because it took me a while to understand that because everybody kept saying disease, disease, disease. And I kept saying, "I don't have a disease," and they're like, "No, it is a disease." I mean, it's something that requires treatment or that there's still a lot of experimentation going on as far as treatments, blood work, whatever else is available out there.

[00:27:30] And then because SRNA also kind of covered a large umbrella, larger than what I was seeing in most, you know, it took me a little while. I thought, "Whoa, this is like above me. I don't belong here," and then I learned that wasn't true. That wasn't true at all. I just put myself out there and I got involved with a couple of the online support groups and just some of the patient day type things, virtual type things. And I liked the people, I liked what I was learning, and I was just like, yeah, this is good. This is where I need to be.

[00:28:12] **Lydia Dubose:** Yeah, that's great. So, the kind of thinking about learning to live with the diagnosis and it sounds like you've sought out a lot of information and you've sought out community. What are some kind of tools that you've found that have helped you on your journey or what are some tips that you've learned about living with NMOSD?

[00:28:38] **Ilona Williams:** Well, for me, the biggest thing is educating yourself. And for me, that also meant putting myself out there, opening myself up to whatever was there, and then it was up to me to decide whatever I was receiving, if it was something that I thought, I don't know if this is I'm headed in the right direction here that kind of thing. And it also helped me just like when I'm meeting my doctors and stuff like that. When I wasn't going to the neurologist, I was going to all these different doctors.

[00:29:14] Now, I have this kind of set up where if I'm going to something that I think might be NMO related and I'm not going to see my neurologist, I still reach out to him and I say, "Hey, look, this is going on, I'm not really sure, like if it's NMO or not, but it's new to me and it is something that I think I should be checked in." And luckily, I have a very good rapport with him, and he has a very good demeanor and I trust him wholeheartedly and he would say, "Okay, fine, no worries."

[00:29:48] So, it had been a while since I had an MRI or something. He's like, "I'll go ahead and send over a script to have for the MRI or whatever else." And so, what I was learning was I had to educate myself because when I was going into these places that were not at my neurologist's office or with my neurologist, the people that I were encountering knew a lot less than I did, even though they were medical professionals.

[00:30:17] Luckily recently I've even had people just be very honest with me. They would say, I've heard of that and the thing that gets me is the biggest thing I've learned from having NMO that it's not MS. Yes, they do share some similarities or characteristics, but it is not MS. When they look at me and they go, "Yeah, that's like MS. I finally learned to say, "Ilona, let the hackles go down" and I just said, "No it's not like MS, it does share some similarities to MS, but it is not MS, and it needs to be treated differently."

[00:30:57] And that's also what I learned having been on MS medication that just because you're taking a medication to treat your disease doesn't mean it's a good thing because what I learned was being on those medications was actually worse for me. It's worse to be on a worse treatment that is not designated for your disease.

[00:31:29] So, now I go in and a lot of times it's funny if I happen to stay, if I go in and I have to stay the night or something like that, I mean, as soon as they walk in the room, as soon as they walk in with anything, the nurse or whomever I'm like, "What is it? Why are you giving it to me? Why do I need it? Why should I take it?" And I also learned that in educating myself that you don't have to accept everything that is being said or

given to you in the hospital. Sometimes I'd be like, "No, I don't think I need that. I don't want to go that route. I don't want to do that."

[00:32:07] And so, that's what I like about my neurologist because when we talk about treatments and things to do, he'll say, "Well, I was thinking about this from what you explained to me. How do you feel about it? What do you think?" He doesn't just walk in and say, "I'm the neurologist. Here take this." I've learned that I don't accept that anymore. So, I guess that's part of being my own advocate.

[00:32:31] **Lydia Dubose:** Yeah, I know that's something that so many people might be dealing with who have NMOSD. Is trying to decide should they be on a long-term treatment? And how do you make decisions about what treatments you take? And how do you feel like you can make an informed decision about treatments? And it sounds like you've done a lot of work for yourself in that area.

[00:32:58] **Ilona Williams:** And my neurologist has been good with that. And so, I am on a long-term treatment, the treatment that I've been on, I've done very well with. And so, again, with all these new things popping up and coming out or becoming available, that's why I also want to continue to try to educate myself and just put myself out there and learn what's going on because I've been doing so well with it. I'm kind of the frame of mind if it ain't broke, why fix it? And I've heard people say, well, isn't it inconvenient? I'm thinking it's my life how's that inconvenient?

[00:33:43] **Lydia Dubose:** I guess since that 2018 relapse. Have you had any relapses since then or exacerbations?

[00:33:55] **Ilona Williams:** No, not NMO-related.

[00:34:00] **Lydia Dubose:** That's good. That's really good. And I know that creating a plan of action is something that a lot of times people end up doing it in case that happens. And is that something that you've done, try to prepare for if something like that happens, or prepare for how things might change over the course of your experience within NMOSD?

[00:34:25] **Ilona Williams:** Well, I mean, it's something you don't want to think about, but it is something that I do think about. Because my mom's kind of in the frame of mind. She's like, "Don't worry about it. You worry about things you don't need to be worried about." And I'm like, "Mom, I don't know how you--I just can't put it out of my head." Having been through what I've been through and now being in a good place, I mean, if this were to change for me again, I'm thinking, "Come on seriously?"

[00:34:57] I don't know. I try to do things like for instance now I live alone, I'm on my own, I'm independent, outside of not working full time or not driving, that I can take care of myself. And I just try to do what I can as far as nutrition and health, and medical wise or medication wise the best that I can to keep me on the right track. And now I also know too when something--and my neurologist is really good. He always says to me, he says, "You know your body better than anybody."

[00:35:35] So, if you think something is not right, I need you to tell me, don't wait for me to figure it out. Don't be afraid to bring it up." So, I'm good about that too. Now I'm past the stage of like every time something happens, I'm not spazzing out thinking oh, no. Sometimes now I'm just kind of like NMO kind of sucks, I'm good here. I'm not downplaying it by any means, but I do kind of have a better understanding of what works for me and what I need, and what doesn't work for me.

[00:36:12] **Lydia Dubose:** Yeah, that's great. What's something that you wish more people understood about living with NMOSD or living with a rare neuroimmune disorder?

[00:36:28] **Ilona Williams:** I feel so bad when I say this because I think to myself as tough as I've had it, there's so many other people that have it so much worse than I do. When I say it's not easy, I mean, life isn't easy but okay. When I say it's not easy, I'm not just talking about myself I'm talking about the fact that luckily times are changing and there's more education out there and more and more treatments are becoming available, and more and more people are becoming doctors. Medical professionals are becoming more aware of what it is.

[00:37:19] And so, when somebody walks in, they're just not, "Oh, she's hysterical. Give her Tylenol. She'll be better tomorrow that type of deal." I don't know. I mean, and the thing is also when I say it's not easy, it's not easy physically. It's not easy physically, it's not easy mentally. You kind of have to learn to balance the two because if one outweighs the other, it's going to be constant, you're going to be in a real struggle, in my opinion.

[00:37:56] **Lydia Dubose:** If you don't mind sharing, what are some things that you do to help the mental side of living with NMOSD. What are some things that support you or that you do?

[00:38:08] **Ilona Williams:** I try to, and my mom is really good about this too. Every day in the beginning if we had a good day, she would look at me and she'd say, "Today was a good day." I'd say, "Yeah." And she goes, "You need to remember this. Today was a good day." And I'd say, "Yeah." So, she has really helped with me being appreciative of just having a good day. When I wake up in the morning, I'm grateful that I woke up in the morning and I woke up and I'm not in any pain, and I'm already thinking about what I'm going to do for the day.

[00:38:46] And the fact that I'm thinking about what I can do for the day because I can do it. I can get up, I can get dressed, I can go brush my teeth. I can get ready to go grocery shopping. I mean, this all sounds like mundane stuff and people do this every day. Yeah, it does but when it's taken away from you and then you have to fight to get it back, you just appreciate it that much more, or at least I do.

[00:39:12] **Lydia Dubose:** Yeah, that's beautiful. That's great. Well, as we're kind of coming to the end of our time here, something that we at SRNA are thinking about a lot is looking towards the future. This year is our 30th anniversary. And so, we're looking back on the last 30 years, looking back on stories like looking back on your story and how far you've come. But then looking towards the future and thinking about what we're hopeful for in the future. So, I want to ask you, what are you hopeful for the future?

[00:39:54] **Ilona Williams:** A cure and as people are diagnosed--and it's nice that these support groups and advocacy groups are out there, no longer being told that the only information that you're getting as soon as you're diagnosed is that you have five good years and then that's it. Because I am past the five-year mark and I'm so grateful for that. I mean, I might only make it to six or seven, but I made it past the five.

[00:40:37] **Lydia Dubose:** That's awesome. Well, thank you so much for sharing your story with NMOSD and the journey that it took to get there, and all that you've been through since. It's really wonderful to hear stories like yours. And I really appreciate you being vulnerable and open to sharing. And before we finish up, is there anything else you'd like to share about your story, about your journey, or anything at all?

[00:41:06] **Ilona Williams:** No, I want to thank SRNA and you for giving me this opportunity, because it's weird looking back on it like when I was going through it, I thought this is never going to change. This is going to take me, it's going to be forever, this is my life forever. And, yeah, it's only been like now I say it's only been five years where if five years ago you would have said to me it's going to take five years. I would have been like, are you kidding? Five years? Oh my gosh.

[00:41:42] And I thank all the organizations for putting out this information for us to have access to it. You don't have to be a doctor or medically inclined to find this information or find these groups. And that's amazing.

So, as you're going through this, no matter what your struggles are, don't forget that there are resources out there. And okay, maybe you might need a little bit of help finding them, but they're out there. I appreciate that. Thank you very much.

[00:42:15] **Lydia Dubose:** Yes and thank you for sharing.

[00:42:21] **Outro:** Thank you to our "Ask the Expert" podcast 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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