

Melanie Flood

You can watch the video of this podcast at: youtu.be/3Uhz6nKeKUs

[00:00:00] **Krissy Dilger:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This podcast is a "Community Spotlight" episode featuring SRNA community member, Melanie Flood. My name is Krissy Dilger, and I will be moderating 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 2023 "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion AstraZeneca Rare Disease, and Genentech. Horizon 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. Horizon believes science and compassion must work together to transform lives.

[00:01:05] Alexion AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist, and they are committed to ensuring that patient perspective and community engagement is always at the forefront of their work. Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops, manufactures, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche Group, has headquarters in South San Francisco, California. For additional information about the company, please visit www.gene.com.

[00:02:00] For today's podcast, we were pleased to be joined by Melanie Flood. Melanie has spent a career advocating for underserved communities in the US and abroad. In 2020, an attack of optic neuritis caused her to lose her vision in her left eye. Being diagnosed with seronegative NMOSD with Sjögren's syndrome and the adversity she has faced since her diagnosis ignited a commitment in her to help other patients with rare diseases. Melanie founded Mellie J Showroom, a European fashion agency based in California and London, which she ran concurrently for 13 years while working in advocacy as the Director of Communications for two trade organizations in the United Kingdom - Social Enterprise UK [a strategic partner of the Cabinet Office] and the UK Fashion and Textile Association - [a trade challenge partner of the Department for International Trade].

[00:02:57] Melanie was also the Director of Development and Communications for Sacramento Food Bank and Family Services. During her time at SFBFS, she developed strategic communications, fundraising, and public awareness campaigns to address food insecurity in Sacramento County. She is currently the Director of Communications for the First 5 Association of California, as well as its complimentary Foundation, and the First 5 Center for Children's Policy. Melanie is a graduate of the American Academy of Dramatic Arts in Los Angeles and the American Conservatory's MFA program. She is a Fellow of the RSA - Royal Society of Arts - and recently became a Regional Policy Task Force Volunteer Co-Chair for the National Organization of

Rare Disorders, NORD. She is currently writing a book about her health journey and is forming a foundation with the intent to shape health policy in California to support the rare disease community. Welcome and thank you for joining us today. Do you mind just briefly introducing yourself?

[00:04:07] **Melanie Flood:** Yeah, my name is Melanie Flood. I am a 47-year-old woman who lives in Northern California, and I have NMOSD with Sjögren's syndrome.

[00:04:21] **Krissy Dilger:** And in regard to your onset of the NMOSD, what age did you start experiencing symptoms and what were these initial symptoms that you had?

[00:04:33] **Melanie Flood:** So, my journey with NMOSD was - I think everyone's is unique. It was interesting. I started experiencing symptoms as a young child. I can remember from the age of seven having heat sensitivity, vomiting from being in the heat on a trip to Arizona with my family when I was nine. I also had anxiety from the age of 11, had depression from - I'd say my teen years, and then the first major episode, I guess what people would call a relapse, was an episode of vomiting and hiccups I had.

[00:05:19] When I was 23 years old, I was in grad school at the time, I used to be a stage actress. I went to the American Conservatory Theater's Master of Fine Arts program, and I was playing Belle on the main stage, my second year during "A Christmas Carol," and I had done about 26 shows and - sorry 40 shows in 26 days. It was a lot, and they were training us for stage and for Broadway and I basically had one day off a week, and I was going through the master's program at the time but also doing a major role on the main stage with professional actors too.

[00:06:00] And so we just finished the show. I had flown to New York for Christmas with a boyfriend at the time. His family was from there and I went to my friends', who I grew up with, who were living in New York, and I had an episode of vomiting and hiccups that wouldn't stop. And so, I went to a hospital there. I can't even remember which one. And they couldn't stop the vomiting and hiccups, and I was discharged. I remember there was an ice storm. I was given some sort of a pill to make the vomiting stop. Ironically, we were in an elevator and there was a gentleman who managed the building. And he was European, and he didn't speak English. I started throwing up in the elevator, mainly just water, and he held my head in this way very tightly that it actually stopped the vomiting.

[00:07:01] And then so fast forward to 10 plus years later as 2013, I'm living in London. I was working at the time. I work in advocacy and I'm a communications director. And again, I've always been a career girl. So, I've always been working a lot and I owned a fashion business at the time as well. And so, I was always thinking I was draining my body, that was what the fatigue was from. And I was having a lot of fatigue, but I had an episode of vomiting and hiccups. And a friend had come over that morning to help me and she looked at me and said, do you need an ambulance? And I had actually lost my bladder and that had never happened before.

[00:07:48] And so she called an ambulance. There were some comments made in the ambulance from the EMTs. I remember them saying something about had I been out drinking the night before. And I had the vomiting and hiccups, and so I was hospitalized for about five days. And then that happened again and then I was discharged. And some terms were thrown around that maybe it was Crohn's disease or colitis, or leukemia. They said I had a very high white blood cell count, but they couldn't find the infection. And six months later I was hospitalized again, and it was a bit more severe with vomiting and hiccups.

[00:08:34] And at the time, I think it's important to mention I was engaged to someone from Europe. He was Swiss and we had canceled our wedding. And so, I tended to either when I was exhausted have

an episode, a relapse, or if something upsetting in my life had happened, I would have an episode like that and be hospitalized. So, that was way back in like 2013 and 2014 that those episodes happened.

[00:09:08] **Krissy Dilger:** Well, that seems like such a long journey to get to the point where you are actually - where you were actually taken seriously and given a real diagnosis. So, I guess take us from there. Was that episode the last one where you were finally given your diagnosis?

[00:09:35] **Melanie Flood:** No, I wish. So, I had crazy fatigue and in my 30s the - I've never lost my bladder, but I was having urology issues. So, I lived in Ireland for a while before London. I had a urologist. After those episodes, they had sent me to a GI doctor because I was having bowel issues. They said I had IBS and all these things that now I know are related to NMO but back then I moved around a lot, but no one was putting the puzzle pieces together. I was certainly giving the information. What my doctors do tell me now, especially my neurology team, they always say you're so good at recounting dates and times, and symptoms, and a lot of people don't remember but like I said, I work in communications for a living. So, I do document things that are happening to me and my symptoms.

[00:10:31] So, I was about 38 at that time. Fast forward to 2020 and we were living in COVID times, and this was August. In the six months leading up to that August, so I'd say from February 2020, I was having bowel and bladder symptoms, but the fatigue was just overwhelming. And I had an aunt who passed from cancer when I was about 30 and I used to say to my sister, "Oh I'm like Aunt Sherry, I have cancer." I just would tell her, "I'm cancer tired. I'm so tired. I don't understand what's going on with my body." And because I had an aunt that had passed from colon cancer, I thought for sure I had cancer.

[00:11:22] And so I would have internal vibrations when I would sleep but I didn't know what they were. So, when my body would get really tired - and this continues. I continue to have this to this day. I mainly feel it when I'm waking up in the morning, my body shakes inside but you can't see it, but I can feel it. And it only happens when I'm awake if I'm in an extreme heat or if I'm really tired. And so, I was having those issues. I was having narcolepsy. I didn't realize it was narcolepsy. I literally was driving to work, and I couldn't stay awake, and it was concerning to me. And so I went to my doctor, my primary. She's fantastic. She started doing a lot of blood work. She found out I had a vitamin D deficiency. She put me on vitamin D dose which now - which I found out later is called an MS dose. And then she continued to do blood work.

[00:12:22] And what happened was come August I woke up one morning and at this time - I think 2020. I would have been 45. I was 45 years old, and I woke up and a few days before on the Friday in my left eye I started noticing these little black clouds and I thought I had put on too much mascara or something, or I hadn't taken my makeup off properly. And I kept rubbing my eye and I wasn't wearing mascara, so I was confused. And then the next day I went out with my best friend, and I told her I was having trouble seeing.

[00:13:10] I thought - because of COVID we all had a lot of Clorox wipes - that I had cleaned, and I had wiped my eye or something. And she put some eye drops in my eye. And this was the night before I lost my vision. And I woke up on the Sunday morning and my vision had come down like a black curtain about half - sorry a third down my left eye. And immediately I knew something was wrong. And I went to urgent care and actually I lived behind the hospital.

[00:13:40] I live in the greater Sacramento region, and I drove to the hospital. And they gave me this red card and they said you need to go to the emergency room. And I didn't realize what it was. And they said can you get there yourself? It was like next door. I was like, "Yeah, I can drive. I've lost some of the top of my vision." I went to the ER. Immediately they triaged me, and they told me they were putting me in an ambulance to UC

Davis. And they thought I had a detached retina. And it was a Sunday, and they didn't have the equipment to operate on me. And they were actually calling UCSF and UC Davis to see if they were available, if they have the equipment there. That's what they said.

[00:14:32] And so they put me in the ambulance. They said it was a surgery but that I would have to have it immediately within 24 hours. And so, I get to UC Davis. And the ophthalmology team comes in and they assess my retina. And then I see a neurology team comes in and they start doing motor function tests on me. And my aunt was actually married to a neurologist when I was young. And I was like, in my head, "Why are they doing motor function tests on me if I have a detached retina?" I was very suspicious, and I started asking questions and I heard the optometrist, or the ophthalmologist say to her colleague who was a resident, "Wow, her retina looks beautiful." And then I knew. And they said, "Well, it could be optic neuritis." And that was the first time I heard those words. And I asked her if I needed surgery and she said, "No, we treat it with steroids." And then that started a whirlwind and that's when it all began.

[00:15:41] It took a while to get there for sure but, obviously, at least they got to it at some point. So, can you just walk me through what the process was like once that determination had been made that it was actually optic neuritis, something neurology related instead of something else? Did your physicians do the blood tests or aquaporin-4 or the MOG antibody? What other diagnostic tests were given?

[00:16:16] So, then the neurology team took over from there and they did a battery of tests. I mean I had a lumbar puncture. They didn't mention any of the diseases they thought I may have, and I learned why later from my neurologist that they don't like to diagnose in the hospital. And so, I didn't know that at the time they basically told me. So, I had a chest x-ray. I had CT scan. I had MRIs. My MRI was over four hours. I mean it was - well, now I get them frequently - but back then it was the head, the brain, the orbits, the thoracic, and cervical spine, then all the blood tests, all the blood work up. And they basically said to me, "We need to rule out everything. We need to make sure that we've ruled out everything and this isn't caused by a virus or bacteria, or something before we start your treatment."

[00:17:26] And so they did. It was 24 hours. And in that 24 hours, by the end of the day - I think it was the end of the first day when I got the first Solu-MEDROL infusions. They were treating me with the corticosteroids. And by then it had completely come down. It was a black curtain all day and it had gone to a pin, and then it was gone. And I could still see in my right eye clearly. And so, they started the infusions. They did three days of corticosteroids on me. And then they sent me home and I was told they had a neuro-ophthalmologist, and I would be scheduled with her, and they would call me - and a neurologist and a rheumatologist. A team would be put together for me.

[00:18:21] And again it was just optic neuritis at that time. I wasn't sure what it was. And then I went in for my first appointment to see my neuro-ophthalmologist. I believe it was seven days later and she did tests on me, and she did visual field tests and she looked at my optic nerve, and they do all the OCT Tests and all those things. And she sat me down and said that it was jumping to my right eye and that I needed to go to the emergency room from her office and that they were going to put a catheter in my neck, and they were going to do what's called plasmapheresis.

[00:19:16] Sorry I get a little - I broke down crying a little bit and she said, "That's every - a lot of people have this reaction. I know it sounds scary." And I'm like, "No, let's do what we have to do." And so, she is a rock star. She saved my vision. Her name is Dr. Allison Lu. She's an amazing person. And I went. They admitted me right in. I got two more doses of corticosteroids because I had had three. And then we started the plasmapheresis treatment and generally, they'll give you five treatments every other day for 10 days. But I was doing so well. They gave me seven. But at the time I had no light in my left eye, completely black, no

vision. And the doctors would come in and out. I had rheumatology teams. I felt like I was an episode of Grey's Anatomy, and I would joke with all the doctors, the neurologists. the rheumatology team would come in. I would say, "oh I'm a series regular on Grey's Anatomy. I'm not a guest star, am I?"

[00:20:34] And they're like, "You're so funny" but I feel like if you can't laugh, you're going to cry. And it's okay to cry but I choose to live in the world where I make fun of what I'm going through because it's so insane and you just can't make this stuff up. And so, I was released from the hospital, and I had no light in the eye, zero. And I was worried that the treatments wouldn't work. And again, I had heard the words NMO from the team that was doing plasmapheresis, actually the day I was leaving. and I had a knee jerk reaction when one of the doctors said that to me because I had other people come in. I had a neurologist come in and he told me I tested positive for Sjögren's. He told me I came up on a panel for lupus possibly but they're actually - that's not in my chart. they're not treating me for that, but I definitely had Sjögren's. And they had sent my lumbar puncture to the Mayo Clinic and that I tested negative for MOG, negative for NMO. And he told me, "You don't want NMO. You do not want that." And we were hoping for MS.

[00:22:05] And I had - I will say this, I had two oligoclonal bands too and so I got out of the hospital and then I met with my neurologist and that's when I was told that they believed I had seronegative NMO, which is an outlier, which is someone who doesn't test positive for the aquaporin-4 antibody. And then he started talking to me about treatment plans. And I should say this too. I was on 80 mg of prednisone from the beginning and that's a whole other beast that we can talk about later. But when I came out of the hospital and all the things that did to my body, but my rheumatologist said no one goes blind on 80 mg of prednisone. And I will tell you that's correct. But it will mess up your teeth and your joints. And I had steroid myopathy which is paralysis and everybody who knows about NMO knows that it attacks the optic nerve and the spine.

[00:23:05] And so when I came home from the hospital in the middle of the night, my best friend, she was staying at my place when I was in the hospital. and her and my sister, and my mom, they were my rock, and she was sleeping in my guest bedroom. and I had to call her at 3:30 in the morning from my bed because I couldn't walk and I thought I was having a relapse and I mean; you can imagine what it's like to wake up blind, which I did, but then to wake up and not be able to walk when you get home from the hospital. But my primary physician, I called her right away in the morning and because I could walk again after the pain was so severe and she told me I likely had steroid myopathy which I did, but that happened twice actually.

[00:24:00] And I had to call my sister at 3:30 in the morning one time and literally pull my body - not crawl because I couldn't walk - pull my body to my front door and open it so that she could come into my house. So, there were a lot of side effects happening alongside with the medication. I always say it's the lesser of two evils. I want to see, and I want to walk but within that other things occur.

[00:24:31] **Krissy Dilger:** Definitely. I just want to say thank you for telling us all this and I know that it must have been such an emotional time and also makes - it would make anyone emotional looking back and thinking about that time. So, just appreciate you talking with us about it today because I do think it will help others who are going through or have gone through the same journey know that they're not alone. So, thank you. But a truly, truly terrifying experience. I'm sure I can't imagine waking up and not being able to see.

[00:25:10] **Melanie Flood:** And I will say this too, in a world of COVID, I wasn't allowed to have visitors during this entire time. So, I lost my vision. Most people have an advocate like a family member. I wasn't allowed to have that because there were no visitors allowed in the hospitals at that time. And this was pre-vaccination days. So, right when I came home, I think it's also important to note, two months after I lost my vision, because of my system was so immunocompromised. they had put me on prednisone, and I was on azathioprine as well until we could start my infusions. and that's what they had decided to do, Rituxan infusions. I got COVID

pneumonia, and I was isolated for two weeks in the hospital in May and thought I'd be fine, but I just tanked very quickly, and I couldn't even walk to the bathroom in the hospital. I had a commode next to my bed for two weeks and I was plugged into the wall on oxygen at home for two months after.

[00:26:17] And so not only did I have to rehabilitate my body and learn how to walk and cook and ride a bicycle and drive and do all these things as a person who had just lost her vision in one eye, but my lungs are permanently scarred now too. And I've never had pneumonia. 2020 was rough. I'm not going to lie. When people complain about their kids not going to prom, I'm like, "I went blind and had COVID pneumonia." I mean, I'm not saying I compare myself to other people, but sometimes I have to, when people complain about things, I just let it go in one ear and out the other because again, my life got so insane in 2020 and it will never be the same. But I can honestly say that I'm in a really great place in my life and I have amazing friends and family and I'm just living it.

[00:27:27] **Krissy Dilger:** I appreciate you saying that because that's something - compounding the fact that you've already been diagnosed with this life-changing disorder then also with COVID on top of it, just nightmare scenario, but you're here as proof standing that you're strong enough to get through it. So, that's awesome. So, I guess we left off where you've gotten home from the hospital, you're obviously experiencing some awful side effects from the prednisone and the other medications. Did your physicians refer you to any rehabilitation? Anything to help with the visual issues you are now experiencing or any physical rehabilitation?

[00:28:16] **Melanie Flood:** No. So, I did have an occupational therapist in the hospital when I first lost the vision. And my neurologist had asked me if I felt that that was useful when I had - and I was very honest with him. he's wonderful. I said, "No, it didn't really help that much. I really did it on my own and I think it was the fear of not having - I have a disability that people can't see. I mean it's not just the vision but it's also the fatigue that I have. And so, because actually Sjögren's is recognized by the State of California as a disability because of the fatigue that it causes. And so having those autoimmune diseases like layered on top of one another, I'm sure sometimes I don't know if it's my medication or the fatigue that makes me tired, but I really just rehabbed my body myself.

[00:29:19] And I've always been very active in terms of hiking. I mean I will say this, I don't run anymore. I did have a little accident on the trail when I decided to hike - some light did end up coming back into my left eye and I have what they call shadow vision in that eye. So, I'm completely blind in it, but I can see the shapes of some things, and it's like grays and blacks and a little bit of white. It's like someone took a hammer to a glass table and like a mosaic pattern and smashed it. That's what it looks like. It did take my night vision. I can almost not see in the dark at all. I don't really have night vision. I do need some light to get around. But again, I just think that you should go towards things that make you feel afraid. So, no, I didn't have a professional help me.

[00:30:21] But my best friend and I, we did go camping and I remember looking at her and saying, "Ali, I think, oh gosh the sun's going down." I had never been out of my house in the dark at night since I lost my vision. And it had been about a year and a half at this time. And she's like, "I've got you." She had a flashlight for me. all my friends they were amazing. They had this big floodlight like by the campground and my other friend she - it was her birthday. She wore this like glitter stick all over her neck. I mean it was great and I think it's important to do those things that make you feel frightened. I'm starting horseback riding lessons soon too and anything that can help with my balance.

[00:31:05] **Krissy Dilger:** Well, that's awesome. That sounds like you've got a handle on it and definitely moving positively in the right direction.

[00:31:16] **Melanie Flood:** Well, and I will say this too. I've always traveled, and I lived in Europe for 10 years and I worked there, but I will say I took a trip, my first trip alone because I've traveled all over the world alone. I moved to Europe alone and I moved to New York alone too when I was younger. And I just wanted to take a trip and so I took a trip in May of this past year of 2022, and it was the first time I got on a plane by myself again. And it was great. And then I had a red-eye flight on the way home and I realized, oh gosh, they turned off all the lights and I'm not going to be able to see again. But I actually had this really nice man sitting next to me and I had dropped my reading glasses and I can't see anything on the phone without my reading glasses anymore. And I just told him. I said, "I'm blind in my left eye. I just dropped my glasses. I can't see in the dark." He was so nice. I mean literally, he helped me throughout the entire flight, but like I said, most people can't tell. And so, they don't know until I'm like, "I can't see. Can you help me?"

[00:32:35] **Krissy Dilger:** Well, that's great though. That sounds like an amazing trip. So, besides the vision, I think you've talked about a little bit of vision issues. Do you have any other current symptoms as a result of the NMO?

[00:32:50] **Melanie Flood:** Yeah, I would definitely say I have bladder and bowel issues. and I have some weakness in my legs and in my arms. And the fatigue is real. The heat sensitivity is probably the worst. And I live in an area where it gets up 112 and 114 degrees in the summer. So, that's been one of the hardest things is to not be able to go outside. I mean I've tried. I've even sat outside having summer dinner at 5:00 and it's only 86 degrees in the shade. And I had a scary episode one time. And I was with my sister and my best friend, and I had to leave and go sit in my car and turn the AC on. So, that's hard. And then just the side effects from the medication.

[00:33:54] **Krissy Dilger:** So, that leads me into my next question. Are you on any long-term therapies to manage your NMO? And what was the process of deciding which if any treatment to choose? What was that process like? And did you feel like you had sufficient information to make an informed decision?

[00:34:15] **Melanie Flood:** Yeah. So, I started on 80 mg of prednisone and then was put on some azathioprine as well in the lead up to Rituxan infusions. My neuro-ophthalmologist, my neurologist, and my rheumatologist had decided together that that was the best course and that's what we were going to do initially. And then we tapered me off of the prednisone. I kept on the azathioprine and started the Rituxan infusions in January of 2021. I was supposed to start in November of 2020, but I had COVID and so that got pushed back. Then there were issues with the health insurance company, and I was supposed to get my Rituxan every six months. Come July when I was due to have my next Rituxan infusion they decided to substitute it with a biosimilar drug called Ruxience which I did not react positively to. So, I ended up having a rash right away and then it didn't work, and I noticed that I was having vision issues in my right eye.

[00:35:27] My neuro-ophthalmologist called me afterhours when she saw one of my tests that I had just completed and told me to go to the ER and so I went for an MRI. We started me on a five-day course of Solu-Medrol corticosteroids again. So, clearly that drug didn't work and only to save the health insurance company a few dollars. I've had many issues with them around my infusions. I changed jobs in the process because I needed a job where I could work from home. I was actually an essential worker during COVID. So, I was the director of development and communications for our food bank for our Sacramento County. And so, we never went home during the pandemic. And it was a wonderful place to work, and I loved everybody there, but I needed to be somewhere where I could be at home and not in an environment where I was around so many people all the time because my immune system was so compromised. And so I changed jobs and when I did that the health insurance that I had was the same health insurance company that I had at my old job. The plan was different however, and they delayed my care which caused me to have some vision lost

in my right eye. I was put on CellCept - a very high dose of CellCept - to combat the vision loss and I had to fight it out. I had to go to the department of managed health care. Luckily at the time my boss in my new job, she helped write the legislation around off-label drugs and she said that's not legal. They can't do that to you because they treat NMO off label. Well, I wouldn't even - the drugs they have approved that you know about that were approved in 2019 with FDA. They wouldn't work on me anyway. I'm seronegative. I don't have the aquaporin-4 antibody anyway.

[00:37:35] And so I had had Rituxan before. It was approved before. I had to go through the department of managed health care with an attorney. I won my case. I got my infusions, but it did irreparable damage in my right eye, so I have black clouds and cuts in that eye. When I used to be able to see more clearly in it and so I'm currently not on mycophenolate anymore which is also known as CellCept. But that drug put me in the hospital a few times because I got a few infections. I got COVID for the third time in June of 2022 and then I had a stomach bug that I got. And so, I continue to fight the health insurance company for my infusions. I'm supposed to be having them in April. They just approved it but they only approved it up through March 31st when they well know I get it every six months and so it's not approved. I'm going to have to go through this process again now and my doctors - one of them said to me, "I've never seen anything like this. Do they want you to go blind and paralyzed? It's not right what they put people through."

[00:39:05] **Krissy Dilger:** I completely agree. It's egregious how often we see this just – we, SRNA, and our community members who have fighting the same types of fights and how it can - you're living example of how it can affect someone in real time, these decisions that the insurance company make. So, I thank you for sharing because I think it's important to tell these stories and bring awareness to this as much as possible.

[00:39:34] **Melanie Flood:** I mean it's hard enough to have a disease that you might not be able to see or walk in your life. That's stressful enough. But to compound that with rejecting a drug that you know will help mitigate those issues. it shouldn't be legal. I have lots of opinions about that.

[00:40:02] **Krissy Dilger:** Yeah, I do as well. So, you mentioned that you have been in the hospital for relapses before. How many relapses would you say you've had and then what is that experience like? So, what do you feel when one is coming on and do you have like a plan of action for when you think you're having a relapse?

[00:40:35] **Melanie Flood:** Well, I think sometimes I'm in the hospital because my immune system is compromised. And that makes me more susceptible to respiratory infections and I think those are very dangerous because most of us know that when you can't be around sick people and so when that happens, I go to the ER right away and I get a chest x-ray to make sure I don't have pneumonia, especially because of the scarring in my lung. I guess when I have like symptoms in my vision, it generally tends to be that mosaic fragmented pattern that I see. I can have pain behind the eyes. What I did forget to mention is a week before I lost my vision, I was in the shower, and I had this insane - it almost felt like I was drunk like I had woken up in the morning. I had gotten in the shower. It was almost like I had too much to drink, and I hadn't had a drink. I hadn't had any wine or anything at dinner the night before and I had to hold myself up in the shower.

[00:41:56] And I remember driving to work and my brain, it was like I was on a sea. And then it went away, and I didn't think much about it. And I actually had like, yeah, I don't know, I dismissed it like you dismiss things and sometimes you think you're middle-aged and you're getting older. but what I will say is I'll get dizzy a little sometimes and then that internal vibration in my body when it gets really strong, I feel like I'm not doing something right, meaning I need to slow down, I need to rest. I need to nap. I need to drink electrolytes. I'm really big on hydrating and also on movement. So, I try to hike as much as I can. I don't hike for as long. I used to go on eight-mile hikes on the weekends. I don't do that anymore. I mean I do about 3.5 miles now, but I think that's still good for where I'm at.

[00:43:06] **Krissy Dilger:** That's awesome. So, are there any tools or tips you have learned since your diagnosis for those living with NMOSD?

[00:43:18] **Melanie Flood:** Well, I guess just being gentle and kind to myself, setting boundaries with people, knowing that I can't do it all because I do think for me personally, it stems a lot from—symptoms will just stem from me being tired or over exhausted, or not feeling like I have to do everything. You know, little things can be hard for me that'll be really easy for everyday people and it's my personality to want to do things that I used to do but if I can't lift something or I can't carry something, or I'm too tired, I just say it. And I try not to internalize what someone might think about me because of it.

[00:44:16] **Krissy Dilger:** I think that's great and that's a great piece of advice because we all are just doing our best, right? And you got to be comfortable in that. And I think that's, that's a really important thing to keep in mind.

[00:44:33] **Melanie Flood:** When people always say, "But you look so well," and they just don't understand the struggle that it is. And I don't wanna wear a banner everyday either. I don't want my whole life to be about that. I'm not asking anyone to—I don't want anyone to feel sorry for me. I'm not a victim but I also—those boundaries need to be respected when I set them.

[00:45:02] **Krissy Dilger:** Yeah, definitely. Okay, so, can you just speak a little bit about how you got involved with SRNA and what your experience has been like as a member of our organization?

[00:45:18] **Melanie Flood:** Yeah, so, I think like anyone, when I first found out what I had, I was very—I didn't wanna go on the Internet. I actually had asked my neurologist, "Should I read anything?" And he's like, "No." He said no and I was really surprised because I like to do research, but I will say I have had my dad pass away very quickly in about a four-month span and was on hospice after a long surgery. And I Googled what he was having and that was a really bad idea because when he passed, Google was actually right in the timeframe that he was gonna die, with what was going on with him. And so, for my own diseases, I just decided not to do that. I didn't think it would be helpful. I wasn't ready to listen to it. I didn't want any advice from anyone. Someone actually told me not to call myself blind or something, which was shocking to me. The things that people will say to you, I mean I am blind and I'm not ashamed of it. So, I don't know why it would make someone else feel uncomfortable.

[00:46:42] But I just—it took me a while and then to just, I think accept where I was. I think when I lost the vision right away, everyone was hoping it was gonna come back but in my mind, I had to just, from the very start, I told myself, "It's not gonna come back and you have to be okay with it not coming back because you have to live your life." And I had a lot I still wanted to do and so, I was like, I was not—and some people, I think we live in a society where people think—I'm a very spiritual person—almost you're manifesting, or you willed this onto yourself. No one is. I have not willed this on myself. A neurologist told me in the hospital, he's like—because I was beating myself up a bit, that I had worked too hard, that I had done this to myself in some way—he said, "Melanie, if you were laying on a beach in Kauai, your body was gonna do this to you. There's nothing you could have done."

[00:47:43] And so, the way I found SRNA is I was ready. It took me several months, about maybe three or four months. I was ready to start learning about what I had and I found—I did a Google search and I thought, "Oh, this sounds great. This is an association for people with autoimmune diseases—or neuroimmune diseases." I've worked in several associations here and abroad, and I loved the educational aspect, and I found the "ABCs of NMOSD." And I listened to one episode and then I'm like, "Okay, that's enough. I'm not ready to listen

to anymore right now." It was hard. It was hard. And then I slowly got through the episodes, and it took me almost a year to get through those episodes and I'm glad I did. And that's how I found SRNA.

[00:48:44] **Krissy Dilger:** Yeah. Well, we're glad you found us and I'm glad to be of any help. But, yeah, those "ABCs of NMOSD" can be a lot of information. So, yeah, I can understand that feeling.

[00:48:58] **Melanie Flood:** It's the acceptance of really facing what you have, and everybody's journey is different, right?

[00:49:07] **Krissy Dilger:** Definitely. So, you recently attended a Disability Rights gala in Sacramento. Can you describe what the purpose of the event was and just what your experience was like attending?

[00:49:22] **Melanie Flood:** Yeah, so, Disability Rights California is the largest actually disability rights group in the nation and they advocate for people with all kinds of disabilities. So, they were holding this inaugural gala—it was their first one—at the Crocker Art Museum and I was really interested in going. I mean, I'm reaching out more into communities that I feel aligned with. You know, I have a job where I work for an advocacy organization and being in the non-profit space for a long time, and kind of being a communications person and a fundraising person to help marginalized communities, in my career, I just was really interested in going as a member of that community.

[00:50:26] And I met some really great people there and was all based in art and disability. And so, they had a poet, and I met some fantastic people there. I took my previous boss that had helped me get my infusions. I took her as my date because she's been such a great patient advocate for me and continues to give me advice on how to fight the insurance companies, which I need on a regular basis, and just support, that I'm entitled to it and that I will get it, and that we just have to persevere. So, that was really exciting, and they do a lot of incredible work in many spaces.

[00:51:18] **Krissy Dilger:** Well, that sounds like a great experience and very important stuff to get involved with. So, awesome that you were able to attend and have a positive experience with it. So, can you just talk about a little bit like what the most difficult parts living with NMOSD are, just what you wish the general public would know about living with this disease?

[00:51:54] **Melanie Flood:** I think the hardest part of having NMO is I used to really plan for the future and it's so uncertain and I guess all of our futures are uncertain. But I live in the now a lot more and I can't say that's a bad thing. But I definitely had to give up any ideas of - I never had a child and I had been thinking about it and I had talked to my doctor about it before I had been diagnosed and it was definitely a possibility back then and now that's not and that's hard. But I also think that I like - again I'm very spiritual and I think that everyone has a path and a journey in their life to walk and this is mine. And so, through that I have tried to do things to - I participate in research studies because I don't want anyone else to have to go through what I went through. I don't want anyone to have to go blind to be diagnosed with something they have or be paralyzed to be diagnosed with something they have. I would love for the medicine, the technology to catch up, the doctors to put the puzzle pieces together, all of that.

[00:53:33] And so I feel like I've turned all of that sadness or frustration into something positive. I'm actually writing a book about my health journey and I'm starting a foundation to help scientific research but also help maybe get some of those health care codes in there that aren't for people. And so, I've just been doing a lot of exploratory work and finding out where my niche is, and I work in the state capital of California, and I think there's an opportunity there.

[00:54:18] **Krissy Dilger:** Wow, that's amazing stuff for sure. I guess my last question - and I touched on it a bit with that last question - but what are you hopeful for?

[00:54:32] **Melanie Flood:** Optic nerve regeneration. I think that's the hot topic for me. Every time I go into my neuro-ophthalmologist's office, I want to hear about grants that the NIH is funding and I always have questions around that and she's very positive about that. And so, I think that I might not be able to ever bring back what I've lost, but it could - research could help combat anything that may happen to me in the future or anyone else living with this disease.

[00:55:15] **Krissy Dilger:** I think that's a great thing to be hopeful for. Awesome. Well, Melanie, I think that brings us to the close of the podcast, but I just want to once again say how grateful we are for you joining us today and being vulnerable and sharing your story. I think the more people who will share their stories, the more people will feel less alone, and also bring to light some of the important issues that we talked about today. So, just thank you.

[00:55:48] **Melanie Flood:** Well, thank you for inviting me and everything that SRNA does. I know it has touched my life very much and when you asked me to be part of this podcast, I wanted to be vulnerable because I don't want people to feel alone and - yeah, just keep going and live your life and do the things that make you afraid.

[00:56:12] **Krissy Dilger:** Yeah. That's awesome. Well, thank you so much.