

# Rare Round Table

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[00:00:04] **Skye Corken:** Thank you so much, everybody for joining us. My name is Skye Corken. I'm the communication and engagement coordinator with SRNA and welcome to our first ever Rare Round Table. Today is Rare Disease Day, a globally recognized day for those within the rare disease community. We're really excited to be kicking it off with this very special event, so thank you for joining us. We have three special guests with us today, Kris Allen who will hopefully be joining us in just a little bit and then Cyrena. Aldelly unfortunately, couldn't make it today. But our guests will be discussing their own personal rare experiences in sharing how they've embraced new normals after their diagnosis. If you do have any questions for our guests, you can put them in the comments section, we'll try to get to as many as we can at the end of the event. But if anything comes to you during the conversation, please feel free to put it there. I will let Kris introduce himself in just a minute. But first, I wanted to give a warm introduction to our moderator for today's discussion. Everybody please welcome SRNA volunteer and Peer Connect Leader, Cyrena Gawuga.

[00:01:29] **Cyrena Gawuga:** Hello everyone. Thank you for joining us for the SRNA Rare Roundtable. I'm really excited to be moderating this discussion. Alan should be with us soon, but for respect for your time and I'm sure a lot of people are really ready to hear what our patients have to say we'll just jump right into this. First, I think, of course, it's important for me to share how I'm part of this community. I have a diagnosis of transverse myelitis and I actually just had my anniversary. My first event was in February 2014. At that time, reached out to what was then the Transverse Myelitis Association. I really valued the resources and just the personal contact. I think a lot of people know that because these are rare neuroimmune diseases. It's not uncommon not to know anyone else and it's a very difficult position to be in. I'm very happy to be able to help SRNA in any way I can and really connect the rare neuroimmune disease community. I'd like Kris to just introduce himself and talk about how he's part of the community.

[00:02:59] **Kris Wilkes:** Hello everybody. My name is Kris Wilkes. I'm originally from Indiana as you can see the jerseys at the back, I play basketball. I went to UCLA for college, and I got diagnosed with ADEM it's acute--I got it propped up right here--disseminated encephalomyelitis. Basically, the myelin in your spine and in the back of your brain, there's a coat over it called myelin. When you have ADEM your body basically attacks the myelin, and it basically just gets rid of the electrical nerves in your body. I was paralyzed from the waist down in 2019 and from there, I've gained the ability to walk again. I've gained my strength back and I'm definitely in a lot happier place than I was when that happened. But that's a little short and sweet.

[00:04:00] **Cyrena Gawuga:** Kris, can you share more about how your life has changed since your diagnosis in 2019? Where were you before and after?

[00:04:14] **Kris Wilkes:** In high school, I was Mr. basketball in Indiana. I was McDonald's all American. Coming out, I had over like 30 division 1 scholarships to go play basketball. Ultimately, I chose UCLA, we're

the number 1 recruiting class. My first year, I was the second leading scorer, 2nd year, I was the first scorer, 1,000 career points and I was projected to go into the NBA draft in 2019. At the beginning of the year, I was projected top 10 and then towards the end, we lost a lot of games, but I was still projected to get drafted. So ironic on the day to get drafted, I woke up paralyzed. For me it was definitely changing, I've had a dream that I was going to go play in the NBA and accomplish my dreams and the day to go reach those dreams, I wake up paralyzed. It's definitely shattered.

[00:05:19] **Cyrena Gawuga:** It's a little bit jarring to your life plans. You're paralyzed now, I know from my experience, I feel like your whole world has been blown up, because you don't know what's going to happen next. But you start to have to live with the condition that you're in. Do you feel like at that time you were capable of foreseeing a new normal experience for yourself? It's a big shift.

[00:06:03] **Kris Wilkes:** I guess for me; I just really didn't know what was going to happen next. When it first happened, nobody really knew. I guess for ADEM, there's really only two places, there's a place in Cleveland and there's the Mayo Clinic in Arizona that specialized in those type of diseases and I was in Indiana at the time when it happened. When it happened, nobody really knew really what it was. They might have thought it was MS or just something different. Just having, all those different doctors coming in and seeing me and not really knowing, what my future holds if I'll ever be able to walk again that's definitely a scary moment.

[00:06:45] **Cyrena Gawuga:** No, I can definitely understand that. I had transverse myelitis, you had ADEM, but we both were suddenly paralyzed, I think, and it's a very disconcerting experience. I was paralyzed on one side. I was in the hospital and the same thing saw lots of doctors, there's all these teams coming at me and for a long time, no one could tell me exactly what happened. I got different like, "Oh, you had a stroke or maybe this is MS." So many different things flying at you, but at the end of the day for me, one of my big goals was I need to walk again. I think for quite a few people would probably have a similar type of thought process. The first thing is like, I need to be moving again. The idea of trying to figure out what normal is going to be after that is a really difficult proposition. Perhaps you can tell us a little bit more about what happened to you afterwards. What did you start to see for your future now that maybe the NBA wasn't in your sight?

[00:08:13] **Kris Wilkes:** Like you say, the first thing is, how am I going to walk again? Am I going to be able to walk again? We went through a couple of treatments with steroids and then the plasmapheresis, those things started to get my feeling back a little bit over time, but I remember coming out and they told me you're going to be in a wheelchair for a while. I don't know for me when people tell me that something's going to happen, especially a negative thing, it always makes me strive to go beyond that and make sure I do that. For me, they told me I'd be in it for a month. I was in the wheelchair for like three days and then I upgraded to the walker and lucky for me, I still have my strength and my arms to be able to move myself around. Just being on the walker for a few months and then after a few months being able to actually start taking my first steps. It was amazing. Then just from there just continuing to be able to walk and then still finding some way to still, I guess, give back to basketball. For me now that basketball was over and they told me that this was, something I probably won't be able to do again. I had to I guess, start thinking of something else to give back.

[00:09:32] **Cyrena Gawuga:** How do you give back to basketball now?

[00:09:37] **Kris Wilkes:** I started a sports equipment company. We started training basketball. It basically helps with the rotation of a person's jump. I dedicated myself into a different path, more of the business and being in it that way. That was what really kept me going.

[00:10:00] **Cyrena Gawuga:** I think it's really important to find a way to motivate yourself. I had a very similar experience. Were you in-patient rehabilitation?

[00:10:11] **Kris Wilkes:** Yeah, for a few months. It's crazy doing simple stuff like leg raise. I would definitely say now I definitely appreciate my legs a lot more than I did before.

[00:10:34] **Cyrena Gawuga:** I think it's really important to have something that motivates you and I think you talked about them telling you or you're going to be in a wheelchair for a certain amount of time. I had that same thought they were like, oh, you're going to be in a wheelchair and then you'll go home on a walker, and I thought to myself that's not going to happen, I'm not going to do that. I recall getting to inpatient rehab the first day and they made me get up and walk and I actually walked. It was with a lot of support.

[00:11:10] **Kris Wilkes:** It's a big script though.

[00:11:14] **Cyrena Gawuga:** Exactly. When I left on a cane and they're like, we've never had anyone come in where you were and went on a cane. I still use a cane and that was something that became part of my new normal. I know a lot of people often think about well, residual symptoms like what happens after your diagnosis, do you have pain? Do you have difficulty walking? Bladder bowel issues. There are a lot of things that happen when you have damage to your neurological system. I think there's a real range of outcomes that people have. Do you have any residual problems from yours?

[00:12:05] **Kris Wilkes:** Yeah, 100%. I guess mine has come more from my bladder definitely had still stuff with bladder that happened back in 2019. Then I guess, would say like sensitivity in my foot, not being able to feel certain stuff or asserting, feelings and stuff has definitely been a big thing.

[00:12:27] **Cyrena Gawuga:** How do you manage that?

[00:12:29] **Kris Wilkes:** I managed it by getting back. Like you say with your cane, I guess it's just my new normal now. Something I don't really think much about because I've been doing it for so long. I'm just managing.

[00:12:45] **Cyrena Gawuga:** Yeah. I think for me, I have residual issues. I mentioned the cane, because I still have weakness in my left leg from the paralysis and a bit of a foot drop, so I use the cane to make sure I don't fall on my face on a regular basis. But I think a lot of people have neuropathic pain that happens after they have a rare neuroimmune incident. I have had neuropathic pain ever since my first incident in 2014. I've actually had three episodes of transverse myelitis. I'm very lucky.

[00:13:28] **Kris Wilkes:** I'm sorry to hear that.

[00:13:32] **Cyrena Gawuga:** You have to laugh about it.

[00:13:35] **Kris Wilkes:** Yeah. But it's still amazing that you're still here and that you're here to still talk to people.

[00:13:41] **Cyrena Gawuga:** I think that's something that's been valuable to is I think a lot of people don't get enough information about what can happen afterward, and pain management is really important and very challenging. I will say for me, I've been very fortunate to work with a neuro immunologist who just sees people who have neuroimmune disorders. He works mostly with multiple sclerosis, but because there is some similarity and one of his patients. I know that people have mixed experiences with gabapentin. But I found it very helpful for me. I definitely know when I forgot to take it.

[00:14:28] **Kris Wilkes:** I think the hardest part about the gabapentin was trying to wean yourself off of it.

[00:14:34] **Cyrena Gawuga:** Well, I still take it. We're all in different places. Right?

[00:14:40] **Kris Wilkes:** Yeah, 100 %.

[00:14:43] **Cyrena Gawuga:** I think the other thing that I've noticed and I'm sure there must be other people who have this as well is temperature issues. I asked about this he said it's autonomic. My left foot is extremely cold. We don't know why. It's something again that's part of my new normal. I used to not sleep in socks, I have to sleep in socks. Now I hate it, but I do it. I think that there's all these little things that come along with a rare neuroimmune disorder, there's not like one doctor you see, for all of the things that come up and it's hard to figure it out, because we are a community with different disorders that can have different effects on the parts of our body, so we have lots of questions that again, maybe show why it's really important to keep engaged with each other. Do you deal with pain at all?

[00:16:05] **Kris Wilkes:** No. I guess not pain, nothing that hurts. I guess one thing I will say though that I've learned is that a lot of times when you have one autoimmune disorder it morphs to another, so for me, I had Crohn's disease first.

[00:16:23] **Cyrena Gawuga:** That's very interesting. I had Lupus first.

[00:16:27] **Kris Wilkes:** I've had Crohn's. It's weird nobody else in my family has Crohn's or any autoimmune. But I developed Crohn's first and that next thing was ADEM, that's what I got out of that.

[00:16:42] **Cyrena Gawuga:** That's an interesting thing too. I think this idea of having multiple disorders happening at the same time. I remember it ultimately took a while for them to nail down that it was transverse myelitis, because the Lupus got in the way of people trying to diagnose things. I think it clouded the waters. I think that probably a lot of people have this issue where they have to negotiate with many different specialties before they figure out what happened to them. Perhaps some people have to see many doctors and over a course of a few years, especially if it's not something that happens, suddenly like mine or yours did. But some people have like this really long progressive

[00:17:41] **Kris Wilkes:** I will tell you it did. I skipped over a little in for like it did. It built up a little bit. I'm trying not to go too much in depth.

[00:17:53] **Cyrena Gawuga:** No. You can. Go ahead please.

[00:17:58] **Kris Wilkes:** The draft was on a Friday it was on 20th June. It was on a Friday. I had a workout in San Antonio about a week before. So maybe like Friday of the last week I had a workout there and when I flew out there to work out the morning, I woke up to work out, I was really sick, I felt really sick. I went, I worked out the whole entire workout. It was okay, but I felt sick the entire time. Afterwards they took my temperature. I had like 103-degree fever. So, they took me over to the hospital right next door and they told me I had strep throat. I couldn't finish any more workouts, I had to go home. They sent me home; I got a flight and went home. A few days after being home, I started getting real bad back pain where my back was just hurting.

[00:18:57] I didn't know what it was, but it kept progressing. Two days before the draft, I had to use the restroom when I woke up in the morning, but I hadn't used the restroom the whole day. My back was killing me really, really bad. I went to like a clinic first and they were like, hey, did you use the restroom today? I was like, no. They told me I need to go to the ER, because you haven't used the restroom today, we can't really do anything about that. I went to the ER I still couldn't go, and I still had back pain, so they gave me morphine. When they gave me the morphine, I still have pain, I still felt it through it. They gave me some more medication

and then they put a catheter in me, to drain my bladder and then they left the catheter in and said, hey, come back in two days, we'll take the catheter out and see where you are then. I went home, hung out with my friends because I had to rent a big Airbnb, because it's for the NBA draft.

[00:20:08] I remember the day before the draft, I had woken up that morning, I dumped my bag out and when I had bent over, I couldn't stand back up. I had called one of my friends, they came in and they just helped me stand up. It was weird, I didn't think too much about it, because it's the first time it happened like whatever. I go sit down on the couch, for some reason I sat there all day, because we were just hanging out. Night-time came about 8:00 or 9:00 pm. One of my friends was like, "Yo, we're going to the gas station, do you want to come?" I'm like, "Yeah." I go to try to stand up and I couldn't stand up and it felt like my legs were like asleep. I was like, I don't know, I couldn't do anything. I'm like, "Hey, man, just take me to the room like something's going on." That's when they took me to the room and that's when I woke up the next morning and I couldn't feel anything. That was it. It progressed a little slow, but it definitely did progress.

[00:21:08] **Cyrena Gawuga:** That's very different from mine. Mine was the course of hours. Like same thing, the back pain and then, a couple hours like my legs started to go, then my arm started to go and the next thing I knew I couldn't walk. It was very shocking. We have a question here. We have medical students from the NYIT College of Osteopathic Medicine. They have a question and I think both of us can answer this, but you can go first Kris. What's one piece of advice you have for young doctors you've learned from your own physician, patient relationships? What would you tell med students?

[00:21:53] **Kris Wilkes:** I guess just when they talk to patients and relationships with the patients, I would say more so, I guess just being encouraging. Just always keeping a smile on your face being happy, because those times can be really sad. They can be real depressing. Just keeping the spirits high. I guess you have to know the person to know, what they really like, but I think overall as a general lesson just keeping the spirits high and just being good.

[00:22:26] **Cyrena Gawuga:** I think from my experience, the most important thing is to listen to your patients and listen to what they're telling you about their personal experience. I keep using this word. But what they're going through, the symptomology that they're reporting and that everything isn't textbook. In med school you learn like things work in a certain way, but in the real world, things don't always present like it is in your textbook. I know, for example, I ran into the issue a couple of times and transfers myelitis. People think it should be like many different segments of the spinal cord, because that's what they learned, but it doesn't have to be like a whole bunch. Mine really was like 1.5, so it was a problem for some people for a while and they thought, oh, this is a stroke, because this looks like a stroke. But it was like the symptoms that we're having, we're not a stroke. Listen to the patient, be open to unique presentations.

[00:23:34] Like Kris said too I think you should be encouraging, and I think it's really important, because there is a range of disability that can happen with rare neuroimmune disorders that you be cognizant of the fact that people can have very productive and successful lives with disabilities. I've personally never had a doctor who told me I can't do X, but I know people who have, and I think it's very important to not tell people they won't be able to do X. Like not tell people you will not be able to walk again unless it's very clear that they won't be able to, because it can be discouraging. I think that people should have the opportunity to try as much as possible. Be encouraging, listen to your patients be open to unique presentations. Rare diseases there can be rare presentation of rare diseases, so be open to that. But I don't know. I think where I would start is just listen to your patient and be encouraging. I think I'll answer this too, but again, Chris, I'll go to you first. What are positive things that have come in the wake of your diagnosis and creating your new normal?

[00:25:07] **Kris Wilkes:** I guess the positive things I would say is being able to do things like this, being able to share my story and being able to show, never give up. Obviously, there are going to be a lot of downs and a lot of things that happen to you in life, but you can always overcome them and just keep pushing forward, I guess would be my thing. That's definitely.

[00:25:34] **Cyrena Gawuga:** What are things that you would say that you've learned from your experience or maybe new opportunities that arose, other than say, sharing your experience here, but other opportunities that arose in the wake of your diagnosis?

[00:25:52] **Kris Wilkes:** Like I said before, they told me that I would never be able to play basketball again and that's always been my strongest goal is to get back on the court and play. Now I feel like I've worked hard the last, four or five years and I've got to a place where my body, my mind and my spirits, everything is feeling like, those days when I did play basketball again. I guess I would say that, just being able to set a goal for something, being able to achieve that goal and work towards that goal. Especially for something like you said before, when they tell you, you can't do something for a lot of people that's, discouraging and I take that type of things and I want to overcome it.

[00:26:44] **Cyrena Gawuga:** You know what, I have a similar answer and that a positive thing that's come from this is I've been able to engage with rare neuroimmune disorders community and also with the Lupus community. I think I remember reading a stat once and like one percent of people with Lupus end up with transverse myelitis. A lot of people with lupus don't know this can happen, so I've had the opportunity to share my story with that. I think also changed my career path. I realized I didn't have the stamina to do laboratory research, so I reoriented myself and I ended up going to social work school, because when it happened, I was actually in a PhD program. I finished that and I thought I can't do this career, because I don't have the stamina for this. What can I do that's different and still going to contribute? I ended up going to social work school.

[00:27:51] I've used my experience dealing with transverse myelitis and all the symptoms I've had to really become an advocate for disability as an identity. I think that we often don't recognize is like 20-25% of the US population is disabled. I think that it's really important to show up as a disabled person who's able to be in the world working, so that people recognize it's still possible. That's something else that I've gotten out of. It is cultivating this disabled identity and being okay with that. We have another question here. It sounds like most of your experience have been in or near a larger city hospital, have either of you experienced symptoms where you needed medical help in a rural community. Have you? Now you mentioned being in Indiana where you in Indianapolis or something like that?

[00:28:58] **Kris Wilkes:** I was in Indianapolis, but I think for a lot of rare autoimmune diseases or just the stuff that we went through, not everybody is equipped to deal with those things. Following back earlier, there was only two places, a place in Ohio and then the Mayo clinic in Arizona that really specialized in ADEM to be able to get you the right treatment to do the right monitoring, to do everything. Because if they hadn't seen that, when I first went, they did take the x-ray of my spine and they did all that, they looked at it, but they didn't know what they were looking for. If I had a place like the Mayo clinic or the place in Cleveland and I went there first, it might have been a different experience. They might have been able to stop it earlier. But I guess the challenges from that is just communicating with the doctor and like you said, just telling them how you feel and the different areas, you're feeling pain or just your different symptoms really is the best way to work those types of systems.

[00:30:09] **Cyrena Gawuga:** I think that this is an important observation is that a lot of the resources to receive the best treatment for rare neuroimmune disorders are near larger cities in hospital systems. I live in Providence, Rhode Island, which has a fairly well-built healthcare system. I also get a lot of my specialty

care in Boston so I'm very fortunate to live along that corridor that I can do that. But a lot of people do have to patch together care, because for example, with ADEM there's two places that really specialize in it. I think that, when you're in a situation whether you're in a rural community or you're just in a community that doesn't have a lot of expertise in your particular disorder, it is challenging, I will have to say and I think probably one of the most important things that you can do as a patient in that situation is to try to reach out to the SRNA.

[00:31:21] I know that they keep a directory of physicians who treat rare neuromuscular disorders, but if you are in a place that just doesn't have anyone who specializes in it, I think that the most important thing is to be as communicative as possible about what's going on with you and what your needs are, because for physicians who may not have seen your disorder before, may not have, experience in the trajectory of what the symptom development. Perhaps if you do, you may have to guide them, and if you say for example, need specialized rehabilitation services, there are resources within hospitals and I can't speak specifically to rural hospitals, because I don't know for sure, but it's always worth enquiring about social service resources in hospitals.

[00:32:27] Most hospitals will have social workers or care navigators that could be able to help you connect with care in other areas and help you connect with resources that can help you pay for it if your insurance won't pay for it. It can be very complicated sometimes, unfortunately, but there is help rather through the SRNA or if you check within the hospital, if they have some social services that you can talk to, to help you start making those connections to, as this question here says, work the system. That's what social workers and care navigators do is work the system. So that could be one place to go to if you're in a smaller community in the hospital and trying to figure out what to do.

[00:33:22] Another question that sometimes comes up it is like this idea of, I don't know, like survivor's guilt in a way. We've said before there's a whole range of outcomes that can happen when you have a rare neuroimmune disorder. I think we're both, walking, functioning and there are people perhaps who don't progress as far. I will say that I've had this moment when I was actually able to walk out of the rehab hospital thinking this could have been a lot worse and then thinking, did I get through this okay? Not too many problems. Someone might look at me and say, well, you have a lot going on, but I would think to myself, well, considering what could have happened, am I doing okay. I think sometimes there is a little bit of maybe internal back and forth about like, oh, why am I doing okay? Do you ever feel that way?

[00:34:37] **Kris Wilkes:** Yeah. Since I've been over to walk again and being able to work out and, do all those, those things that could do before I got injured, now be able to do that stuff now has definitely made me feel happy. It could have been worse, I still could be hurt, I could be very much like you, still have to use a cane or anything and not having to do that is definitely a blessing.

[00:35:16] **Cyrena Gawuga:** I would definitely say that. I still think I'm very fortunate. The problem is when you have a rare neuroimmune disorder is that it's so dependent and your outcome can be very dependent on who you have access to and who you are able to build into your care team. For example, my neuroimmunologist and my rheumatologist worked together in a hospital system, so they communicate regularly. But that's just the luck of being in an area with a lot of health care providers all in one place. A lot of people don't have that. There is a certain level of, I don't know, privilege guilt, coming from medical privilege.

[00:36:24] **Kris Wilkes:** For me, I had two main doctors that I saw while I was in the hospital and while you're in the hospital, they're all hands on. But as soon as I came out, it was a lot different. It was either hard to get in contact with them or it was hard to get medical records to send it to the Mayo Clinic. So, it was a lot of struggles after coming out of the hospital I guess I would say for me and even communicating with the rehab team, they never communicated with them either, so I didn't have that privilege to be able to have them all like a team per se.



[00:37:09] **Cyrena Gawuga:** What's your medical team like now? What kind of providers do you see?

[00:37:16] **Kris Wilkes:** On a regular everyday basis, I don't really see anybody now, as much as I used to when I was still on medication for my Crohn's, but I was able to suppress that and change up my diet and stuff so I could get off that medication. For the ADEM I was only on the medication that you were on the gabapentin and stuff. I was on that for probably about like a little less than a year and then I came off of that. Right now, I'm off of all medication right now. I'm moving good right now.

[00:37:56] **Cyrena Gawuga:** Oh, we have a comment here and I think that this is something that's really important to point out to people. Thank you, Nancy for saying this. As much as possible, keep your records together in some way. Keep a list of all of the doctors that you see, all of the medications that you take, whatever diagnosis you've had, how many times you've been in the hospital, all of that stuff. Whenever I see a new doctor, I have a document on my computer and I actually also have this in my iPhone, but I just hand them this thing. I'll tell you it has sped things up. Everyone's on a computer and so they have to enter everything, and I just give them this document. They're like, wow, this is amazing, because we've just swept away 30 minutes of just data that they can just type in and now we can have a real discussion.

[00:38:54] Like you really want to make sure that you have, I guess your history together, because there's so many times, you're going to see physicians who know nothing about you and probably know very little about whatever rare neuroimmune disorder you have, even if their neurologist, you might not know. You want to make sure that you're able to keep everything together, who you've seen when you saw them, when you were in the hospital. It's important as much as possible to know what treatments you have, your medications and their dosages, the phone numbers, emails, if they have them, whatever it might be, just keep it all together. It's good for your knowledge and it also facilitates care when you can sweep away a lot of that stuff that you have to talk about.

[00:39:50] **Kris Wilkes:** I apologize for my dog.

[00:39:53] **Cyrena Gawuga:** That's fine. I had to lock up my cat. I think that's something that's really important to recognize is like keeping yourself together in terms of your medical information can often help make treatment move along faster. I think really the new normal it's different for everybody and we all end up in different places and there's no reason to feel like you failed in some way, because you aren't walking. It's been almost 10 years, but I can't run, and I like that is part of my new normal. I can run about a block and then I start limping. That's fine. That's where I am. Everyone has a place that becomes their new normal doesn't mean you don't stop trying, but there are things that just change for you. I think the important thing is to recognize that your life is going to change.

[00:41:03] I think we both demonstrated that our lives have changed some for the better, some maybe not as great, but it's your life. Oh yeah, Alan, this is exactly the same. A lot of people may not have this option, but if you can go to one hospital. I go to two hospital systems, but they communicate. But that's a lucky thing. I just wanted to point out that Alan was supposed to be with us today, but we had a little technical difficulty. Yes, if you can be in one system, so everybody can communicate. But again, that's a new normal. If you didn't have this before, you may not even thought about the fact that doctors need to communicate with each other. Any final words Kris?

[00:42:00] **Kris Wilkes:** No, it was a pleasure you guys having me. It was a pleasure being able to share my story, give some feedback and answer some questions.

[00:42:09] **Cyrena Gawuga:** It was really nice to meet you. It's so great to really just be able to meet other people in the rare neuroimmune disorders community. Literally the first time I met people is when I went



to RNDS last year. I think it's important, for everyone to know that there is support. That's RNA is here. We have a peer connect leaders who are people that you can reach out to through SRNA, people like myself who have had some rare neuroimmune diagnosis who can just talk to you about your experience and share information, whatever support you might need. We're here SRNA is here and we're ready to help you learn what your new normal is.

[00:43:11] **Skye Corken:** Well, thank you everybody. I just wanted to pop back on really quick and give the biggest thank you to our special guest, Kris and Cyrena for opening their hearts and just sharing their time and stories with us today. It really does make such a big difference and it really does help raise awareness. So, thank you so much. Also, a big thank you to our audience members wherever you are joining us from far and wide. Thank you so much for helping us kick off Rare Disease Day 2023.