

Voices of SRNA Volunteers

Part 2

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[00:00:02] **Lydia Dubose:** Hello and welcome to SRNA “Ask the Expert” podcast series, “Community Spotlight.” This podcast is titled, “Voices of SRNA Volunteers.” 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.

[00:00:36] For this podcast, we are pleased to be joined by Minaal and Doug. You can view their bios in the podcast description. Well, hello, Minaal and Doug, it's great to talk to you both today. Welcome and thanks for being here.

[00:00:52] **Minaal Zahid:** Great to be here.

[00:00:54] **Lydia Dubose:** For a little bit of background on our discussion, I just wanted to share SRNA was founded 30 years ago. This year, we're celebrating 30 years of SRNA, and it started out entirely as a group of individuals volunteering their time to come together to find support, to find information when it was entirely volunteer-run and operated for a long time. And today volunteers continue to be a big part of what we do at SRNA. And so, I'm really excited to be here talking with both of you who have generously given your time as volunteers with SRNA. So, let's start by getting to know each of you. If you'd like to just introduce yourself, share a little bit about who you are, where you're from and how you first found out about SRNA. Doug, would you like to get us started?

[00:01:49] **Doug Kirby:** I'd be happy to. I was diagnosed with NMOSD in 2017, almost exactly seven years ago. It was in March of 2017. I live in Utah. I have a wife, and her name is Holly, and she actually does a lot of the volunteer work with me. We try to do things together. We have five kids and eight grandkids, and we're heading towards—not there yet—but heading towards retirement. And so, this disease affected me a little later than it does some people. But I've tried to make that, or take that as an advantage as I work with other people, that I have some life experience that I can share.

[00:02:39] **Lydia Dubose:** So, thank you Doug. Minaal, would you like to introduce yourself?

[00:02:42] **Minaal Zahid:** Yeah. Hi. I'm Minaal. I'm fourth year medical student at NYITCOM. The way I found out about SRNA and my journey throughout medical school was really inspired by my brother. I'm the oldest of, now, four siblings. Back then, it was three, when my brother—he started having symptoms of NMO. So, ataxia and visual disturbances. He was around, I want to say, seven years old, and I was around nine, and then it took around a year for him to get diagnosed with NMO.

[00:03:22] So just that experience really propelled me to pursue neurology and medical school. And I'm here today waiting for match day. And I found out about SRNA specifically just because I wanted to get involved within the community of neuroimmunology, and I had some time on my hands in third year of medical school. So, I'm like, "Why not? This is the perfect time to get involved." So, yeah, I was just really lucky that I was able to find this organization.

[00:03:53] **Lydia Dubose:** Awesome. And that leads us into what I was about to ask, is there a specific turning point or motivation that led you into getting more involved in volunteering? When you were seeking out volunteering, were there certain types of volunteer activities you were looking for? Minaal, I'll ask you that first.

[00:04:13] **Minaal Zahid:** Yeah, I think for me definitely as a medical student being on the receiving end of standard medical education, I will say we didn't really get a lot of neurology exposure, let alone neuroimmunology exposure. So that was definitely something I wanted an organization to focus on, was educating the public. And that's why I was really excited when SRNA had ideas to make these booklets to be more accessible to the public or just being really motivated to creating these public platforms where people can connect with family members or people who are affected by these diseases and just having the general public know like, "Oh, this is their experience, this is what they're going through, and this is something we should become more aware of." So, all of those reasons, which is why I was really happy to be part of this movement.

[00:05:08] **Lydia Dubose:** Awesome. Thank you. And Doug, how about you? What was your turning point, or what led you to getting more involved as a volunteer?

[00:05:16] **Doug Kirby:** And I didn't really answer your first question. So, I completely became aware of SRNA, I think just through web searching, trying to find information about this new disease that I had and found SRNA that way. I actually started volunteering for another organization initially—I still do. And the more that I read the content on the SRNA website, I felt like I wanted to be part of that community, it seemed like a well-thought-out, well-organized, great information and it just seemed like a good place to be.

[00:05:53] And the volunteer part is... as you go through something difficult in life, and all of us will and all of us have, the hardest time perhaps to reach out and help others is when you're going through that experience. But in spite of it being the hardest time, it's probably the best time to do that, because it helps you get out of that little space that you might find yourself in as a result of being overwhelmed with new information coming your way. And it allows me to grow, to get to know people like you folks and many others, people that I would never have ever met in my little corner here in Utah, and I just would not have had that experience.

[00:06:40] So I have found that volunteering and reaching out and particularly trying to communicate and meet one-on-one or one in groups with people has been so beneficial to me and made me feel I'm welcome. It makes me feel like I'm part of a larger experience or family or group or whatever term you want to pick there. And so, I guess, my reason for doing this honestly is a little selfish, because I want to feel better about what I'm going through and that helps me to do that.

[00:07:13] **Lydia Dubose:** It's great to hear the different paths that lead you into this common experience of volunteering. So, now let's dive into more specifically some of the different ways that you have volunteered or been involved with SRNA. I know, Minaal, you mentioned you've been involved in helping with developing some of our resources and educational materials, and you also hosted a Rare Disease Day event last year in 2023. Can you describe a little bit about what it was like to be a part of those projects and also how volunteering fits into your life?

[00:07:59] **Minaal Zahid:** Yeah. So, I guess this was the third year of my medical school. So, we were still really busy with rotations, but I had that—during my emergency medicine rotation, we had little pockets of time just because it was a shift schedule. So that's how I got in touch with SRNA. And I was really excited about how willing the organization was to put whatever idea I had and be totally gung-ho about it. I was like, "That's awesome."

[00:08:29] And I was very excited to host some form of Rare Disease Day event. I just didn't know where it would be or how exactly it would formulate. And then I got the idea of like, "Oh why not just use my medical school? It's a pretty large medical school. So, I think there would be a bigger outreach." And also, it was just a way for me to fulfill what I felt like was missing in my medical education in the first two years of medical school. So, it was really fun, and we formulated the event timeline as the months went on.

[00:09:10] We had ample time, thankfully three months, to plan it. And it was really, really cool, because I got to collaborate with my school faculty as well, Dr. Leder. So, she also gave a lot of input and helped make it happen. So, we had trivia, we had speakers, we had a panel of patients and their caregivers give their input. And it was really shocking to me how much the medical students like my peers loved it, which I guess it shouldn't have been, because we're neurology nerds. But still, it was really cool how much people liked it, especially people who could relate. We had somebody who had an uncle with CIDP talk about their experience in the audience. So that was very unexpected. But also, wow, of course, you're not isolated in your own world. So, it was a great experience to just connect with other peers and educate peers, as well as myself, honestly.

[00:10:08] Other work I've done with SRNA and longitudinally is "the booklet project," is how I like to describe it. But we're taking these diseases that might seem really complex and trying to paint them in a way that the general public or a new patient might understand a person going through this. It's a really difficult time, and I know my family, we had a lot of questions, and we didn't even know what the disease was. So, I think something like this would have been really helpful for us back in 2005 or whenever my brother was diagnosed. So, I really feel like it's really needed and I'm really happy to be a part of this public education outreach movement that SRNA is facilitating. So, I think it's been a fun ride, and I can't wait to contribute more.

[00:11:10] **Lydia Dubose:** Awesome. Thank you so much for bringing your creativity and your experience and fitting it in between medical school and all that entails. How about you, Doug, can you share a little bit about how you volunteer with SRNA, how you're involved with our support groups or other activities, and how it fits into your life?

[00:11:30] **Doug Kirby:** So, my primary volunteer work with SRNA is hosting a monthly support group with my wife, the two of us host that, and we just have done that for probably a little over a year now and just really enjoy that. We've met a lot of people. We've heard a lot of similar stories. We've heard some dissimilar stories. I think my favorite part of doing that is when someone who is newly diagnosed joins the group for the first time. And as they hear the experiences of others and you can only see it in their face, you can certainly hear it in their words when they express how grateful they are to know that they're not alone. I can't tell you how many times I've heard that over the last year: "I am so glad to find out that I'm not alone. I'm not the only one that has this disease." Because all of these diseases are quite rare.

[00:12:23] And the other thing that I hope to try to do, and I don't remember who taught me this, but somebody said the best way to start a conversation is to ask somebody about themselves, because we all like to talk about ourselves. And I found that to be true. And that's why I work on asking questions that will draw out individuals, and nobody in our group—and so far, it's all been on Zoom—nobody in our group needs to turn on

their mic or their camera. And to date, we've never had anybody not do that. So, we're able to get everybody involved, and they're comfortable talking and telling us their story, and occasionally I'll get an email that I can reach out and respond to or someone will email me and say, "Oh, I was going to try and come this month, but I can't, I'm so sorry," because they enjoy that so much.

[00:13:16] And I got to be honest with you, it's just such a small investment for such a big reward. So, for me, it's worth every hour and a half that we spend once a month doing that. So, thank you for letting me do that.

[00:13:32] **Lydia Dubose:** Well, thank you for giving so much of your time. I know it might feel like bite-sized pieces every month, but it adds up to a lot. And you've already spoke to this, but I wanted to ask if you wanted to share anything about what impact do you feel volunteering makes and what's been most rewarding? If you have anything else to share about that, Doug.

[00:13:59] **Doug Kirby:** Maybe I can be more specific about what I said a minute ago. First of all, the biggest reward honestly is to myself, it's to me. Sometimes I'm a little tired at the end of a workday to have to sit down for another hour and a half and have a conversation, and I'm by nature, an introvert. That was a little difficult for me, but I always feel reenergized and charged at the end of that hour and a half, and it goes by so quickly.

[00:14:26] And again, the big payoff really is those first-time people that come and they're so excited to find out they're not alone and then to watch them mature over maybe several months, and they're not the first-time person anymore. Now, they're the individual that has some experience, and they can share with the new first-time person. So, it's really interesting to watch how that group evolves. And we don't always have the same people, but there are three or four that seem to come, or they'll come for three or four months and then they've had enough. And that's okay. But it is enjoyable to me, and the payback is watching the growth that happens in individuals as they go through that phase. That first year is really, really tough.

[00:15:09] I've been seven years ago, but I still remember how every little thing that happens, you worry that you're going to have another relapse. And so, when we can help people understand what's going on during that first year and virtually hold their hand through that process is rewarding.

[00:15:33] **Lydia Dubose:** Absolutely. Minaal, how about you? Can you share a little bit about what impact do you feel that you've been able to make as a volunteer and what's been rewarding for you?

[00:15:43] **Minaal Zahid:** Yeah, I would just like to comment on Doug's really beautiful sentiment of giving back when you're at the hardest stage of your life. I think that's definitely something I wouldn't have considered as my first thought of what to do when you're going through a tough time. But I definitely see the beauty in it, and I think it's something other people definitely benefit from. And I think it's something my brother probably wishes he had, but times were a lot different back then, 15 years ago.

[00:16:12] For me, I think the most rewarding thing is seeing my brother and my family also respond to my volunteering and getting more involved in the community. So, not necessarily like SRNA, but just the general neuroimmunology community in general. It's just really cool to see them get out of their shell and connect with other people. We were at the Samara Foundation's New York City event recently, and we were able to meet Gigi over there, and that was a really cool experience. I didn't expect to see her. We also met Krissy over there as well. So just seeing my family respond, because they've went through this on their own when it first happened 15 years ago, and you get mixed information, especially back then when the disease wasn't as clear as it is to us today or definitely not the medical options that we have now for NMO. So, it's just really nice to see them being more connected.

[00:17:16] And the other thing, for me, is this new generation of people who are having these rare diseases. I think just having this foundation, or being able to build this foundation. So, then they come across our website on the Internet and being like, "Oh, I'm not alone." Like Doug said, it's just really cool to pave that way and hopefully enrich one person's life with information they might not otherwise have known.

[00:17:48] **Lydia Dubose:** Yeah, it's awesome. And it's amazing to see how much change has happened in the last 30 years, 10 years, 15 years and what could be in the future, too. And thinking forward for you both, and you have different contexts that you're coming to this community through. What do you hope to see in the future related to rare neuroimmune disorders? Are there changes or advancements that you hope to see? And whenever you have an idea of what this community looks like in the future, what comes to your mind? Minaal, would you like to go ahead?

[00:18:30] **Minaal Zahid:** Yeah. So, I guess for me, from the medical side of things, the way I would really love to see more of a push is, aside from the acute phases of these diseases when they happen, I think people often overlook the chronic psychological effects and the cognitive effects that these diseases have. And especially within cognition, I think it's something that the community has started to explore a little bit more, but it's definitely not where we're at compared to MS. NMO for example, isn't as well studied within its cognitive impact. So that's definitely something I think is really important, especially for those who are diagnosed a lot younger.

[00:19:14] And what does that implicate for their future and their working lives? I think that's something I would love to see grow further. And also, on that topic of working and activities of daily life, I think that's also something that people might overlook in an acute phase versus a chronic phase. What are we doing to support this person to find a job or get the care that they need at home, or if they're immobile, how are they getting around? So, all of these like factors that might seem somewhat not as important during the acute phase of the disease, I think that's something physicians might want to explore further, is how do we chronically help these people?

[00:19:58] **Lydia Dubose:** Oh, that's great. How about you, Doug, what do you hope to see for the future?

[00:20:02] **Doug Kirby:** I appreciate what Minaal said, because I agree that you don't want to be defined by your disease, but there are things that need to be different as a result of that and sometimes it's hard to find those. So maybe I'll go to the other end, the acute portion of these kinds of diseases. I'm reminded of a story. My daughter has a friend who was in medical school, probably just maybe a year ahead of you Minaal, in Texas.

[00:20:28] And they were going through their slides of rare diseases all in one day, and they get to the NMO slide, and the doctor said, "Don't worry about this one, you will never see it." And went on to the next one, and he was aware of my disease. So, that caught his attention. I went to the ER four times with symptoms that, someone who would have been aware of that set of symptoms that I had, would have connected that NMO right away and got me scheduled for an MRI, and I likely would not have some of the disabilities that I have now.

[00:21:03] And so I think that the group that we should work harder to educate are that first line, that ER group, because I didn't know it was a neurological disease. I had the hiccups, and they wouldn't stop. And some other things going on, but none of them were neurological for me. But the symptoms grouped together—someone who had had a little education or more than five minutes in medical school on this particular disease might have known. And so, I think we can probably do a better job of educating the neurologists and the ER people and Minaal with her background she's going to be tremendous with that.

[00:21:48] But it's even hard to find a neurologist once you are diagnosed that's comfortable treating you, because they're not seeing patients with NMO. They're used to treating MS and other neurological issues. But I would be in better shape today if one of the four ER doctors that I had seen before, or at least three of them, would have picked up on this and helped me out differently. And I don't blame any of them, by the way, they just didn't know. But if they could have known, if they would have known, there are other things I would be able to do today that I can't, and I don't hold them responsible for that. I just think we need to do a better job in educating them.

[00:22:34] **Lydia Dubose:** Yeah, a lot of work to be done. And it's great to have folks like you and others involved in SRNA who are helping us get the word out and helping spread that message. It's great to see. So, we've learned a little bit about you both. We've learned a little bit about some of the ways that you've been involved in the SRNA community and some of the ways that you've been involved as a volunteer. What would you say if somebody is considering maybe getting more involved, if somebody is thinking about, "Should I volunteer? Should I do something? What can I do?" What would you say to them? Doug?

[00:23:19] **Doug Kirby:** So, if I can go back to what I said earlier, first of all, I wanted to say something else. If you want to be happy, if you want to be productive, if you want to feel like you're doing something good, you have to make an investment. And sometimes we don't all have a lot of money, we don't have a lot of other things. Maybe we could donate or whatever. We all have time, and for the return that I get for the little amount of time that I invest, it's huge. I wish the stock market worked that way because I'd be able to retire. But it doesn't. But volunteering does work that way. It doesn't take a lot of time. It takes focus when you're doing it. But the reward, the boost that you get to yourself because of how other people feel for the work that you've done.

[00:24:13] And Minaal, maybe you don't see that as clearly as I do, because you're working with books and other things that you're writing. But I can tell you, whoever put the materials together for SRNA when I started reading them helped me a lot, and that was really important to me to have that work done so that I could know what was going on and have something that I felt like had some scientific backing. So, I'm sorry, I'm rambling a bit. But that little investment in time, big payback, I think is the takeaway.

[00:24:51] **Lydia Dubose:** That's great. How about you, Minaal?

[00:24:53] **Minaal Zahid:** I definitely am echoing Doug's sentiments here. I think people sometimes overestimate how much time we have to invest to get such a wonderful output. I think it's definitely something that I just put in a little bit, maybe every week or every month, whichever you can afford to do with your time. Even as a medical student in third year, I think it was very peaceful for me, because it was just something that I was very passionate about. And I think, where there's a will, there's a way. I like to live by, "You don't have time, you make time for things." And even if it's just an hour in your day, I think that just the payback, like Doug said, that you get from building this foundation or connecting with other people is just so rewarding.

[00:25:41] It definitely brightens up my day whenever I'm able to interact with Lydia or other SRNA members, and just being like, "Oh, I'm putting something positive out into the world." And maybe it's for selfish reasons as well, like Doug said before, but it definitely does make you feel better about yourself. And I think it also positively impacts you professionally. I think it just gives you so much scope to connect with other people. And there's a whole world that you can get involved in and learn more about what you like to do and what your career will be in the future. And even if it's not professionally or something personal, I think the reward, at the end of the day, it just really touches my heart, and I think communities around the world can feel the same.

[00:26:34] And that's also something I forgot to mention, a future goal of mine was, I think, definitely broadening our community internationally is something I think would really help. And it's also a personal goal of mine. I'm also rambling a bit, but overall, it's small-time investment for a really big reward.

[00:26:56] **Lydia Dubose:** Yes. Thank you so much for sharing and no worries about rambling. I love hearing your thoughts and both of you, you have so much that you bring into this. So, as we're wrapping up our conversation here, I just want to open it up to both of you. Do you all have anything that you would like to share or that you would like to ask one another before we finish up here?

[00:27:27] **Doug Kirby:** So, Minaal, you were talking before we started recording about what your future holds. Could you take just a second and tell us where you'd like to go and what you'd like to be? You talked a little bit about that.

[00:27:40] **Minaal Zahid:** Yes. So, my goal is to be a child neurologist. I found out I matched this Monday. Tomorrow, I will open the figurative and literal envelope of finding out where I match. I'm going to give a hint and say it's really close to Lydia is where my Number 1 is. So, God willing, I will be a pediatric neurologist somewhere really warm.

[00:28:09] And yeah, I guess, my question to Doug is, so you mentioned the three emergency medicine physicians, and that's also something that I also thought about was educating ER doctors or just physicians in general, not just emergency medicine physicians, because that is something that we see in medical school when we rotate, is how other doctors cross over and teach each other. So, that's something that I think would be a really cool project, is to help doctors crossover, especially neurologists teaching EM physicians. I think that would be really awesome, because they are definitely the first line we have in health care. So, having that knowledge in their toolkit, I think, would be amazing.

[00:28:57] **Doug Kirby:** I agree with that. And we know that physicians have to have continuing medical education, right? I forget what they're called, but they do have to do some training and get the hours, so they can keep their license, and somehow, we need to figure out how we can get into that path. And I think the two groups are neurologists and people that practice emergency medicine because obviously most people that start with this disease don't know where to go other than the emergency medical facility. And so, whatever we can do there. And they're such a busy group. I've talked to a couple of them to ask them how we might do that, and I haven't got a good response yet, but we'll continue to think about that.

[00:29:45] **Minaal Zahid:** Yeah, definitely. I'm going to have to search for all the ER docs tomorrow, the future ER docs, and be like, "Let's make this coalition happen."

[00:29:56] **Doug Kirby:** And I think part of that is to do with the size of the hospital and where you go. If you go to a very large hospital, you might find somebody that gets it. The hospital that I went to is good size, initially, but it's rural. So, they just didn't know. And I don't hold anybody responsible for that. I don't hold any grudges. My life would be different if that would have happened. And I'll be honest with you—maybe what I'm going through and the opportunity that it gives me to volunteer and just to get to know people. And we went to a lot of patient days last year, and people that have enriched my life—maybe it's worth not being able to type with this hand. Maybe that's a fair trade off.

[00:30:56] **Lydia Dubose:** Well, thank you both so much. I love all the vision that we have for the future and what could be and if we put our heads together, what can be accomplished. I'm really excited for the future and really appreciative of all the time that you've given of these past few years of being involved with SRNA

and just appreciate you both being willing to be open about yourselves and about your personal experiences. Really, I just feel so grateful that you're a part of our volunteer community. We have so many awesome people who are connected to SRNA, and so I love getting to know each of you all. And I'm just so grateful for your time and thank you so much for being here and for sharing.

[00:31:44] **Doug Kirby:** Thank you.

[00:31:46] **Minaal Zahid:** Likewise, Lydia. Thank you. This is a great opportunity.

[00:31:54] Krissy Dilger: 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.

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