

# Journey Together

## Reflecting and Shaping the Future of Rare Neuroimmune Disorders

You can watch the video of this discussion at: [youtu.be/8pk-a0JeRq8](https://youtu.be/8pk-a0JeRq8)

[00:00:04] **Lydia Dubose:** Welcome to SRNA Stronger Together. Today is Rare Disease Day and we're so excited that you've decided to join and be a part of this event. My name is Lydia Dubose, and I am the Community and Volunteer Engagement Manager for the Siegel Rare Neuroimmune Association or SRNA. If you haven't already, please take a minute for everybody viewing to introduce yourselves in the event chat and share what brings you to this event, what Rare Disease Day means to you, and your connection to SRNA.

[00:00:39] Today, I'm joined by Donna, Kyra, and John, for this community roundtable session. We will be reflecting and thinking about the future of rare neuroimmune disorders, and we're grateful to you all for joining us. So, Kyra, John, and Donna, please take a moment to introduce yourself, share where you're from in the world, a little bit about your background, and what your connection is to SRNA. John, would you like to go first?

[00:01:16] **John Filchak:** Sure. My name is John Filchak. I live in Connecticut. I'm a public policy professional, I guess is what I call myself, for the past 40 years. I was diagnosed almost two years ago with MOG. It has changed everything for me and my focus, and all. So, it's been quite an adventure.

[00:01:52] **Lydia Dubose:** Thanks, John. Donna, would you like to go next?

[00:01:54] **Donna Sharp:** My name is Donna Sharp. I'm in the UK, near Cambridge. I'm actually retired, although my background is a variety of things, publishing, and teaching. I first went down with this, I got transverse myelitis November 2022, and was subsequently diagnosed with neuromyelitis optica, which was the cause of it. And like John, it's certainly been very, very life changing, but here we are.

[00:02:41] **Lydia Dubose:** "But here we are." And, Kyra, how about you?

[00:02:44] **Kyra Mazer:** Hi. I am attending from Saskatchewan in Canada. I am a pharmacy assistant, a student. I enjoy adaptive sports, but I'm here because I've been living with MOGAD and transverse myelitis since September 2022. I was almost fully paralyzed from about T6 down, but I've regained a lot of mobility. So, I'm pretty proud of my journey. And SRNA has been a really important part of, I guess early in my journey of learning more about my disease and making me feel more connected to other people with rare neuroimmune diseases, because otherwise I don't know if I'd meet someone in person with MOGAD.

[00:03:36] **Lydia Dubose:** Awesome. And welcome, Andrew. Sorry, I got you on here a little bit late. But if you would just introduce yourself and your connection to SRNA?

[00:03:47] **Andrew Jopson:** Hey, thank you, Lydia. I just want to also -- I was having technical issues, and you're leading the session and getting me in, I really appreciate that. And that's testament to the team at SRNA. So, my name is Andrew. I live in Baltimore, Maryland, but I grew up in Northern California. And I was

diagnosed with neuromyelitis optica spectrum disorder in May of 2022 after my first attack. I'm actually a PhD student at Johns Hopkins University and that was actually during, while I was -- well, I'm still a student, was when I had my first attack, and my care team there also was able to connect me with SRNA while I was still in the hospital to see about resources, and I joined the young adults support group. That's actually where I met Kyra as well. And that's how I've gotten more involved in this community.

[00:04:46] **Lydia Dubose:** Awesome. Thank you all for being willing to be here and share your experiences. It truly shows how we're all stronger together. There's all these different experiences, different diagnoses, different places in the world, but this community brings us together. So, I'm just going to open up this question and y'all can unmute and speak to it as you feel comfortable. But thinking about your journey with your diagnosis, what are some key lessons that you've learned, and what's been a big help to you as you've learned how to live and find your new normal and life after a diagnosis of a rare neuroimmune disorder?

[00:05:37] **Donna Sharp:** Shall I go first? Well, the key thing I've learned and also from talking to other people during this past year is that prompt diagnosis and treatment, which often doesn't happen I have to say is absolutely key to recovery and how well you recover. I was incredibly lucky. My local hospital has a fantastic neuroimmunology team, and my GP was very good in sending me straight to A&E, which is emergency department in the States.

[00:06:22] So, from it first starting, about eight days from the onset of the pain, which I just thought I trapped a nerve or whatever to hospital admission was eight days. And within four days of hospital admission, I had started treatment, they still didn't quite know what was going on exactly. But within 48 hours of being admitted, I had gone from my limbs not working quite as they should to being completely paralyzed down my left side. And obviously they suspected neuromyelitis optica and they sent the blood swab, but they have to be sent to a specialist lab in Oxford here, and they take some time.

[00:07:14] But in the meantime, they put me on the standard treatment here, which is intravenous steroids, followed by intravenous IG, and hoped that that would work. I didn't have PLEX because that was decided against. I know we have slightly different protocols in the UK than you do in the States. And indeed, within a couple of days of having that treatment, I'd started to get tiny, tiny flickerings in my fingers and in my toes. So that was encouraging. And they were very reluctant for me to go home, but I did get myself home just in time for Christmas, only because we'd been able to put in a stair lift, all the other things that go with being disabled.

[00:08:11] And basically, I had to walk again. I've had to learn to use this arm, but here I am a year down the line, and I absolutely know that the reason I have recovered as well as I have is because of the speed of diagnosis and treatment. And I also know that there are many, many people, both in the States and in the UK, and good hospitals that don't get that. So, raising the awareness for that is really, really crucial. So, I will stop there and let others share their experience.

[00:08:49] **John Filchak:** I would fully agree with that. When I had my initial attack, I went to a local hospital actually a couple of times and was sent back saying, it's a reaction to a vaccine that I had recently gotten. I kept deteriorating and to the point where I actually had a stroke, and I was hospitalized locally. They ruled out anything neurological and I was treated for meningitis for a couple of days. But thankfully, my doctors are actually in Boston, I was able to get up there and they have an incredibly robust neurological expertise.

[00:09:41] So, they quickly got me onto, first on the prednisone and IV on that and then the blood plasma transfers, five of those. Now I do IVIG every four weeks, but I was 22 days hospitalized, and I think it could have been a lot shorter if there was that knowledge, but unfortunately there wasn't. They were trying hard, but if you don't know, you don't know. But since that time, I've really immersed myself in anything I can read

on MOG, and SRNA has been, you know with your library and all, has been a tremendous help, maybe I know too much at this point, but I'd rather know more than less.

[00:10:40] **Kyra Mazer:** I think something that's been really important to my healing journey has been connection with others. SRNA has definitely provided a great platform for connecting with other people with my diagnosis. But finding in-person groups has been important, too. I don't know if anyone else within my region has MOGAD, but I'm trying to find other similar groups, for example, we have a group called Spinal Cord Injury Saskatchewan.

[00:11:10] And so they've been really important to connecting with. I attend a women's group to be able to discuss womanly problems with spinal cord injuries. But I've even found other groups have been open to me attending such as MS. So, I have quite a few friends in the MS community, and I find that they're very understanding to my troubles, and they want to learn more and such. And so, it's been a very sympathetic supportive group.

[00:11:44] So I would say, I would encourage people who are feeling still a sense of loneliness, who maybe haven't found groups outside of digital groups, to try to connect with other groups that may be related, because from what I've found they can be very supportive even if they don't have your exact diagnosis.

[00:12:13] **Andrew Jopson:** I completely agree with Kyra. Just connecting with other folks, talking with other folks who are in the same age group as me has been a huge part of why I'm even here. I think I would also just want to add, two things that I've learned in the last year and a half were that just as we always are working on relationships with our family post diagnosis or friends who are now coming to know you in a different way, I think I've learned just the importance of building relationships with my care team.

[00:12:45] I think there's asymmetry in terms of how much they know about versus you, and you can educate yourself as much as possible. But ultimately, your symptoms are your symptoms and your experience. But I think I've learned how important it is. So, I'm seronegative for NMOSD, and also, I've been diagnosed with Lupus and Graves' disease, and so all these autoimmune conditions.

[00:13:09] And I deal with a lot of different specialists. I'm in an environment where my specialists do communicate quite a bit, but I often have to be I think the captain of that ship, which is a really uncomfortable space when I don't know that much about this illness. But I think I'm only able to navigate just when blood work comes back weird, or this medication isn't working that well for me, being able to communicate that across. And it's really iterative over time. I feel like they're trying to figure out or get me to trust them, and I need to trust them.

[00:13:47] So I would just say like, continue to work on building that relationship with your providers that hopefully it's beyond just like, "Oh, you're in here for 15 minutes," and, "Oh, looks all good. See you later." But to really do the work of letting them know about things that are going on in your life as well that could be also just driving factors in the symptoms.

[00:14:07] And then the other thing I also just want to say too is that I think is critical for us, especially going forward, is access to facilities. I'm in a position where I can take a free shuttle to where I can get all of my care. And I know that I won't always have that when I leave where I'm at. And I think that that's something-- access to facilities quick and easily was a huge part of my recovery.

[00:14:42] **Donna Sharp:** It's quite interesting because we're all saying a similar thing in that I think certainly from my point of view, I got by luck the most fantastic care and treatment, and I will be forever grateful for

that. But then I was discharged with nothing, no support, no pointers, absolutely nothing to the extent that I have actually spoken to a specialist nurse and raised this, and she said quite openly that she doesn't do social media, but she understood that lots of people did, and I've actually put together a list of where people can go and she's very keen to have that.

[00:15:29] And this is the thing that's come back time and time again is that people are discharged, but they've got no pointers at all. I mean, we've got the Transverse Myelitis Society here in the UK, which is really excellent. But I had to find that, I had to find all those groups. I'm quite tech savvy, but a lot of people aren't, a lot of people aren't on social media. So, there is no sign posting to support other people. And it is a very, very lonely place when you're discharged.

[00:16:02] And I'll be quite open about the fact that I was in a very dark place when I came home. I could do nothing for myself. The shock and the trauma were beyond imagining. If I could have spoken to somebody like me who said, "Look, this was me a year ago and look where I am now," that would have made a huge, huge difference at the time. I've had to find that, and I hear that time and time again. And it seems to be— I mean, finding SRNA has been absolutely fantastic, but there should be, I don't know how we do it, but all the hospitals that are treating us should discharge their patients with at least say, "Look, here's a list of groups that you can contact." That doesn't happen and it really must.

[00:17:01] **John Filchak:** I fully agree with that, and that was my experience as well. I get discharged, "Okay, now what?" And I was referred to an initial neurologist within that same hospital system, whose specialty was MS, knew of MOG, but that really wasn't his focus. And thankfully, at that point, I had found SRNA and was reading more and more about it. And I kept asking him questions to the point where he finally said to me, "I think we need to get you to a different neurologist who knows more about this," and readily transferred me over to another one who had expertise in what I have, and that really changed the course of what the treatments were.

[00:17:48] So you have to be your own best advocate and just keep asking questions, which is just critical to this. And in my case, my wife has been incredible. When I wasn't really in condition to ask questions, she's pretty dogged in on those things. So, you need to be an advocate, you need people around you to help, and don't be afraid to ask questions.

[00:18:21] **Kyra Mazer:** For myself, I was discharged from the hospital just about a year ago. And after that, I had outpatient physio. And following that, I was referred to a program that I don't know where I'd be without this program, it's offered through the health region, and you can get referred to it if you've been through rehab. And it's essentially a workout program ran by—they have an exercise therapist, an occupational therapist assistant, and a physio. So, they help you to adapt gym equipment if you're in a wheelchair or they also have some special physio equipment, but I know it's a pretty new program. So, if it was just a few years ago, I would have been in a similar place where I don't know what therapy I would have had following hospital.

[00:19:15] But because of this, they've been with me every step of the way and as I progress in learning to walk and such. So, it's been incredibly beneficial, and it definitely pains me to hear that's not everyone's experience. But I think programs like that are much more needed and should be more widespread because otherwise people's rehabilitation journey can definitely be cut short.

[00:19:44] **Andrew Jopson:** And I think along with just so much of, a huge part of my rehabilitation was being connected with a rehab therapist that I could talk, like a psychotherapist, to really process the trauma that Donna has talked about, I think each and every one of us after that first attack or if you have a relapse. But I think even also just in living with the uncertainty, if it's a relapsing condition, I think I had a really hard time

after I was discharged, and actually I was in the middle of moving. So, my lease ended on my apartment. So, I was discharged from rehab and expected to be out of my apartment in two weeks. And so actually, while I was in inpatient rehab, we were trying to find me an apartment in Baltimore that I was on the third-floor walk-up, which was just not going to happen anymore.

[00:20:37] And so I'm totally with you, Donna, around what can hospital do to really think broadly about what this person's needs are going to be, and the things that they had before, they might need other things now. And so, I do agree that this ongoing care management or care coordination is really essential for folks as they navigate how to live differently.

[00:21:00] Along with just, I think, having access to just a rehab psychotherapist or even just any therapist who really understands what it's like living with a chronic illness or dealing with a new diagnosis is really essential for folks, and that should be really also part of care afterwards. But I think that's also allowed me to get to a place where in dealing with the uncertainty about relapsing or trying to figure out, "Is this a symptom of a relapse? What's going on? Is this happening?" I've learned a key part and I'm still learning this is how to approach a lot of this uncertainty with curiosity about myself.

[00:21:41] And I think that allows us, as John was saying, to ask questions like, "Hey I'm feeling this in my body. Is this something else?" And I think I've become a much more curious person. I mean, that's the reframe I think that's been helpful for me around, either what I'm eating, or just how I'm living my life and what are my priorities in my life. And to really--I think that's been a key part of my recovery and learning to live as I am, given all of these things, it's like, "How do I approach and reorient myself around living with this rare condition or the unknown of it with more curiosity about life?"

[00:22:29] **Donna Sharp:** I understand what you said about having a relapsing condition and "Is this just a normal neuropathic pain or am I having a relapse?" That's really quite tricky to navigate. And the pain is always there, it never goes, but some days it's very much worse than others. And I think, "Oh God, am I having a relapse?" I self-triage myself the whole time and I think, "No, I can still move everything, even if it's painful, I'm not getting any numbness anywhere. Just hold tight."

[00:23:15] So, I haven't actually taken myself off to hospital in a panic yet. And like you say, Andrew, you do start to read your body a lot more and become very much more self-aware because you have to, because as you say, you've got to advocate for yourself the whole time. And that's quite a challenging place to suddenly find yourself in virtually overnight. But the other thing I wanted to say was about physiotherapy, which is just absolutely key. It really is.

[00:23:51] Over here in the UK, it is slightly different. I was referred to the community physiotherapist, but obviously with funds being the way they are and demands on their time, the community physiotherapist didn't materialize until I've been home for about four or five months, I think. In fact, in hospital knowing how serious this was, I had already made contact with a neurophysiotherapy group that I knew of, and I was in the fortunate position of being able to do that privately. So, the minute Christmas was out of the way, I had my first appointment with her, and she's just been absolutely amazing. And I'm still continuing to see her, I see her three times a month. And I don't think I'd be where I am without physiotherapy in place. But I think for people who aren't in that fortunate position, what on Earth do they do? It's scary, seriously scary.

[00:25:05] But again, here in the UK, we've got a chap who developed transverse myelitis, I think, about 3 or 4 years ago, I'm not sure now. But anyway, he was very seriously ill but has recovered, and he wanted to give something back and he has done an amazing fundraising project and he's raised loads of money. And he now gives grants to people in this country who need physiotherapy, but nobody knows about him. I know

two or three people that he's helped, but so many people aren't aware that that resource is available to them if they want to apply for it. So, everything, all the information is so fragmented, nothing is pulled together, and that seems to me to be the case both here in the UK and in the States.

[00:26:01] **Lydia Dubose:** There's so many resources and so many parts of the experience that you've all spoken about. There's the physical recovery, the physical response of working with your medical team, and then the emotional side of coping with your diagnosis, learning to live with your diagnosis, and all the different ways that that shows up in your emotional and mental well-being. So, it sounds like there's a lot of similarities between you all and you all had great advice related to each of those. Is there anything before we move on that y'all would want to share about tips for those who maybe are earlier on in their journey or who aren't in the place that you're at currently?

[00:26:54] **Kyra Mazer:** I'd maybe like to touch on something that Andrew briefly touched on, and just learning to live with your diagnosis. I think some of the best advice I received early on was to not focus too much on the past and not as in grieving is important and it's healthy, but constantly wishing for the way things once were isn't necessarily helpful. So, what's a way to, I guess, look forward? And I guess for me, that's been practicing gratitude and focusing on what my body can do versus what it can't. And so how I've learned to practice that, and this has been very helpful with my trauma and coping every day is just trying to gently rewire my thinking. So, pretty much every day, I'll have a thought, for example, of I really wish I could do a challenging yoga session and that's something I can't do any longer.

[00:28:09] I allow myself to acknowledge that like, that's important with grieving, but then I try to follow it with a positive thought of, "Hey, maybe I can't do a yoga session, but I am strong enough now that I can do my favorite yoga pose. I can get into a forward fold." So, trying to acknowledge those difficult feelings that way has helped me so much in regaining positivity, and it becomes more natural over time. Like I said, I think it really helps me focus on what my body can do. And so, I'm just still so grateful to have some level of functioning.

[00:28:52] **John Filchak:** I think that's a great point. And early on when I was back circulating in work and seeing people, one of the things I'd hear more often than not is, "So now you're cured," and you give your explanation about no, you're not. But in your head, you're saying, "Is there going to be another attack?" And moving on, that was difficult in the first many months after the diagnosis and getting back around. It's easier now because I've been able to process it better. But I have to say that was a real challenge to move forward, which I think I've done a better job at this point. But in the back of your head, you're saying, "Well, what's going to happen tomorrow?" So, it does change your outlook.

[00:29:55] **Donna Sharp:** The other thing I would say to anybody who's very early on in their diagnosis, is it is amazing what the body will do and how it can recover, and whatever situation you're in and you just cannot imagine ever being able to do anything normal again. And it will come, and obviously the more that you can help it by doing physio and things like that, the better. But the body will heal. You won't necessarily be exactly as you were before, but you will still be able to function in a way that at this point you might not be able to imagine, and you must really hang on to that, because it is a fact.

[00:30:49] **Lydia Dubose:** All great nuggets for folks who can learn from your experiences and thank you for sharing. So, shifting toward, we've been reflecting a lot on your experiences and a lot in the past, and now I want to shift us to looking forward a little bit more. Looking at the big picture of the rare neuroimmune disorder community as a whole, what are some of the ongoing needs that we as a community should focus on? I know y'all have already voiced a little bit of the medical system being able to have resources that people are

handed as they're moving on from acute care, from rehab. But what are some of the ongoing needs? You can reiterate ones you've already mentioned or what are some other ones that haven't been discussed already?

[00:31:50] **Donna Sharp:** Well, on the wish list, there are things that one might be able to achieve or improve. There are also things that might not be possible. But on my list, I've got effective pain relief and neuropathic pain because there are so many different drugs out there, it's so individual, and nothing really seems to work. So, I would personally--I know I'm not alone in this, would like to see much more research into that because living with neuropathic pain I've discovered is a whole different ball game to anything else. It's not just taking a couple of paracetamols, it's something else entirely.

[00:32:32] Effective pain relief would make a huge difference to an awful lot of people. Obviously a "cure" for NMO. Also because we have this specific condition but we also straddle all sorts of other things as well, that we tap into the spinal cord injuries community, which could have a spinal cord injury for any number of reasons.

[00:33:03] But nevertheless, we can still take a lot from that on one of the things. And I know there's research going on in this country under the multiple sclerosis banner. But myelin sheath repair and research into that, which I know is going on, because that could make a huge difference to all of us and other people with spinal cord injuries. If we could repair the myelin sheath, it would make a huge, huge difference. So that's my wish list.

[00:33:40] **Lydia Dubose:** That's great research to be done.

[00:33:44] **John Filchak:** I think making sure, thankfully hasn't been the case so far with me, but to enable the physicians to--if they decide on a treatment path and not being encumbered by the insurance world. And I know that the more I read, that seems to be for a spectrum of diseases, especially when there's no approved treatment as is the case with MOG and others. I think that's one that needs to continue to be worked on.

[00:34:25] And also with my experience in a small hospital and I know it's a rare disease, but I keep going back to, if it had been caught, what can be done so that rather than just simply they test and say, "Well, it's not MS, so it's not neurological," which is essentially what happened. There is some other additional means to get them to dig a little deeper so that we can get the treatment. If I've been put on steroids immediately, it wouldn't have changed the diagnosis, but it probably would have changed spending 22 days hospitalized. So, I'm not sure how that would occur. My primary care doctor didn't know what I have, but she's educated herself on it and she's become a real champion for me and looking at all the test results and discussing it with me and really giving a 30,000-foot view of what I've got in addition to all the great specialists I have.

[00:35:51] **Donna Sharp:** This is tapping into the need for much greater awareness, both within the medical profession and the general public as well. I mean, I'm not making comparisons or disparaging them, but if somebody gets a diagnosis of cancer or stroke or whatever and you tell somebody that, they immediately get it, plus the fact that there's an awful lot of support out there. But you tell somebody that you've got transverse myelitis and neuromyelitis optica, they just look at you blankly. There just is not the awareness out there. That includes the medical profession as well, because I know that statistically a GP might see one case in his whole career, maybe not even that. An awareness raising campaign I think it's on the cards.

[00:36:54] **Kyra Mazer:** My personal hope is to one day be able to connect more regionally with people with MOGAD. I haven't found any group that represents MOGAD within Canada. And although I feel very digitally supported through SRNA, it would be really nice to be able to connect with people who I could discuss common challenges, I guess, with healthcare. I would like to learn more about people in other provinces of

Canada, how their healthcare compares to mine. So, I don't know what the disconnect there is, if there's just not enough diagnosis within Canada or we're just too small. But some way to connect with people when there's not enough of us to create a larger support group would be really nice.

[00:38:00] **Andrew Jopson:** I think one, I mean, for me being a double seronegative NMOSD, I think, has made it even harder for me to think through what my prognosis is. And even get that uncertainty and it sounds like probably in the next 5-10 years, we might identify and figure out, there's like a lot of momentum to figure out what's going on with those who are double seronegative. And it's quite possible soon it might just be in the same way that we found out about MOG that it'll be something else and we'll be able to maybe better classify and figure out treatment options and prognosis for those like me. So that's been my big hope in this, I think.

[00:38:47] And I think related to that, and this is just maybe particular to me as well as, because of this uncertainty about like, "Well, how do we treat this? We're not really sure for those who are double seronegative," like, I'm always worried about the way that I just like over utilizing services. I'm going in and getting tested for a lot of different things, and other things end up popping up for me that lead to other paths. Last year, regular blood tests for something led to, "Let's just do a scan." And then we did a scan, and of course, you'll find something, and that just led to this snowballing effect around me being just in all these testing, even though symptomatically I felt okay.

[00:39:42] And so I think, I don't know, I mean, some people would argue like, "Well, that's great that you're getting all these tests and they're actually investigating, because I can't even get them to investigate." But I think just somewhere in between that, because I found that the more that I just continue to interact in these healthcare systems that they're just going to continue to find more and more and more, rather than taking a symptom-based approach around like, "What do I actually care about as a patient to live my life rather than me just making appointments, doing really intense scans. What is most important to me as a patient so that I can continue living my life?" And if it's managing symptoms like pain, 100%. That needs to be the priority so that you could do the things you want to do, or access to devices that allow you to do activities that you want to do and grow in that way.

[00:40:39] So, I don't know, that's my thought, especially because we're heading in a direction where we just have more and more advanced technology that we can just use and use. But to what extent is that actually helping us to live the lives that we want to live? And I don't want to interface entirely within this healthcare system all the time. I want to spend more time outside of it. And I think the more time that I do spend in it, the more that I think about myself differently, it's just always sick or always a patient and I'm trying to move and imagine myself differently. So that's been something I think a lot about in terms of the future.

[00:41:21] **Donna Sharp:** Well, I think too, we also have to hang on to the thought that we are "some of the lucky ones" in that it really wasn't that long ago, 10, 15 years ago, that we would quite possibly have been diagnosed incorrectly with MS, for example. I mean, it's only very recently that the aquaporin and MOG antibodies have been discovered. So, certainly about the last 15 years, I think that they were discovered. I think I'm right in saying that. And that was a huge thing to identify NMO as a quite--it has similarities to MS--but a quite separate condition.

[00:42:07] So, obviously, there's much more research to be done, but we are in a more fortunate position than perhaps people would have been 20, 25 years ago. As one of the professors who was looking after me said--he was on the research team and he said, "We do know so much more now than we did not very long ago." So that's something that we do have to hang onto, and also tap into that knowledge as well, which I know everybody here is doing. But that's really crucial that we do it for ourselves.



[00:42:44] **Lydia Dubose:** It's amazing to look back. That's something we're doing in a big way this year with SRNA's 30th anniversary, looking back on the past 30 years and how far we've come. Donna, that's such a good point to remember to look back and to have that perspective. We're looking forward to the next 30 years. What do the next 30 years hold and what changes will be made in the future? A couple of you had already mentioned what you're hopeful for the future, but do you have anything to add about your hopes for the future?

[00:43:26] **Donna Sharp:** Just to carry on improving. I mean, I'm 14 months down the line and the recovery window is the first six months you make the most recovery, but the recovery window is actually two years, and I have to keep reminding myself that I'm still well within that two years. And the body does go on repairing itself. We have to remember that. And the more we make our bodies do and encourage it, then the more we will improve. It doesn't just stop, it does continue, and we have to remember that and also pass that on to others as much as we possibly can.

[00:44:17] **John Filchak:** I'm looking forward, actually in 10 days I'm going to actually meet people that have MOG. I've done, as you say, the digital meetings, and that's fine and it's good, but I've never ever met anyone with it. So that's going to be exciting to me to actually have a conversation with individuals where you can actually have that up close and personal interface, because Zoom is great but it's not the same.

[00:44:57] And I'll just say too, when I get my treatments each month, I get the blood tests and I did have one that had an abnormal result come back. I have to say a little bit of panic came in that I'm not going to go to a local hospital because they don't know what I have. So, I made a decision to go into Boston into an emergency room, they are in coordination with my doctors. It turned out to be just an abnormal test but there was that couple of hours of internal panic of, "What's going on here? Is this something compounding with what I had?" It turned out to be nothing, but it's a little bit of stress.

[00:45:50] **Donna Sharp:** You don't need stress because that triggers your symptoms again, doesn't it?

[00:45:55] **John Filchak:** That's right. Well, I was actually on a golf course when I got a call and they said, "I need you to come into the emergency room." I don't play golf like I used to after this, but I keep trying.

[00:46:08] **Andrew Jopson:** Know when you get a call from a doctor, they're calling you rather than you saying, "Hey, hey, hey, hey." That's really scary because, especially--and for me also, I almost got rid of the MyChart to access my blood test results, you get a notification as soon as you go get blood work, you're not feeling that great. You get the blood work, and you get the notification, and then you see the blood test results before your provider has a chance to review. And you're like, "Oh, my gosh." You're in panic mode and then they say, "You know what, this is okay. Let's retest this next week." And you're like, "Great." And that can mess up your whole day.

[00:46:50] And so I'm totally with you. I had to say like, "I can't see these results before my provider does." I think it's important to stay informed. I'm with all of you. I think most of us in the rare disease community, we want to be the more--we have to be. We feel obligated to be the experts. We know that we're interacting with providers who don't know what's going on. And yet sometimes I don't like being so informed and so aware and ahead, because again, it's nice. You want to be the captain of your ship and sometimes you just want to let someone else take over for a little bit for you and I think just navigating that, that's what I hope to do over the next 30 years.

[00:47:31] For myself, I'm looking forward to living most of my life post, like after having this attack, and trying to imagine what that looks like myself, and maybe we will see a cure. I think that's actually the way

that technology is working. We might. I mean, I'm totally, it's hard for me to imagine that we wouldn't, given just everything else that's just advancing. But I really do hope that I am able to navigate this ongoing testing, ongoing sort of how I navigate the uncertainty is what I really am hoping to be better at over the next 30 years.

[00:48:19] **Donna Sharp:** And MyChart is truly wonderful, but it is-- you're quite right--it's very much double-edged. I'd much rather, I'm very glad we've got it because I know of other people who just cannot get hold of their medical records of any sort whatsoever. But the flipside of that is you're lying in hospital, getting increasingly paralyzed and your results, as you say, are coming down the phone and your doctor hasn't even seen them. But it's a wonderful resource. We're very lucky, those of us who have access to MyChart.

[00:48:55] **John Filchak:** One tip that I would give, and follow is I never--or I try to avoid a Friday appointment so that when I get that result and I have to--it seems like it's always a three-day weekend and waiting till Tuesday is not...

[00:49:14] **Donna Sharp:** Yeah, it's not fun.

[00:49:16] **John Filchak:** Not fun at all. So, I'm definitely a Monday through Thursday person on those things.

[00:49:25] **Donna Sharp:** Another tip I'd pass on, and I have no idea whether this would work in the States or not. But out of the Transverse Myelitis Society here in the UK, very recently a WhatsApp group has developed from that, which one of the members very kindly agreed to start, and it's only been going, I don't know, six, seven weeks, maybe two months. And that has been an amazing resource. I think there's only 24 of us on it, obviously, we're all in the UK.

[00:50:02] But so many of the people have said this is fantastic to have this because they can fire off a question, immediately get information back from other members of the group as to what's helped them with that particular thing. And that has proved to be a really amazing resource, and also, they don't have to wait until the next month's Zoom call.

[00:50:26] So, if you can find people in your area, Kyra, for example, you would like to find people in your area with MOG, and if it is practical to set up some sort of WhatsApp group, I mean, obviously it can't be too large, it would be unwieldy, that has proved a fantastic resource for us here in the UK. So, it's something worth thinking about if you do find those people.

[00:50:54] **Lydia Dubose:** So, it's been awesome and so much wisdom, so many good tips and advice and sharing just between each of you, and this has been just a wonderful conversation. And I appreciate you all sharing and reflecting and hoping and envisioning what can be with us. So, it's been fantastic. In our last just couple of minutes here before we move on to our next session, do you all have any final words to share?

[00:51:30] **Donna Sharp:** Just onwards and upwards.

[00:51:37] **John Filchak:** You got to keep going forward. And I'd say in some ways, it's an odd thing to say, but I'm a little bit more at ease with myself with the diagnosis, or maybe I've looked more inward, a lot more optimistic, I guess, going forward than I thought it was going to be when this first came out. So, it is, initially, you could say devastating, but I think I've moved on from that state. It's always there. I think there's reason for hope for the cure and better treatments, and I think just going forward positively.

[00:52:36] **Lydia Dubose:** Wonderful. Well, thank you all so much. Thank you, Kyra, John, Donna, and Andrew, for taking some time to chat and share with our community.