

## Updates from SRNA Staff

You can listen to the audio of this talk at: <https://youtu.be/YupFoyDxgfm>

**GG deFiebre:** [00:00:00] Hi, everyone. My name is GG deFiebre. I'm going to just be talking a bit about the Siegel Rare Neuroimmune Association, or SRNA. So again, my name is GG deFiebre. I'm the Associate Director of Research and Education at SRNA. We're an organization that was founded in 1994. We are a team of 10 people, who Jeremy is one of, one of those, 10 people that you see on the screen as well here. We support over 15,000 of our members from 121 countries, so all around the world. This is our team. We're a small team, but we're small, but effective, so, you know, you might see some of these faces in the chats, so feel free to reach out to any of us about any questions you have about the organization.

[00:00:51] So again, SRNA, we are formerly the Transverse Myelitis Association. We advocate for and support and educate individuals and their families with these diagnoses that we learned about earlier today. We also accelerate and invest scientific research, therapy development, and we also train clinician scientists who are dedicated to treating individuals with these disorders. So, of course, our end goal is to improve the quality of life of individuals with rare neuroimmune disorders.

[00:01:21] So just very briefly what we do. We have several disorder information sheets available on our website. All of... we have sheets available for all of the disorders, and they're, you know, easily available. You can print them out, and they're all reviewed by members of our Medical and Scientific Council. We also publish peer-reviewed research summaries, so oftentimes people don't have access to academic journals, so we try to summarize them so that they're easily accessible.

[00:01:50] On our website, we also have a resource library that has over 400 resources that include podcasts, symposia videos like from prior symposia, newsletters, and other resources.-We also do our rare neuroimmune disorder symposia, we're having one at the moment. We do one every other year, and then on the off years, we usually do a regional one and this was, of course, supposed to happen in Utah, but here we are today virtually.

[00:02:16] We also have two podcast series. We have our Ask the Expert podcast series on all of the disorders. We do these monthly or more, and then we also have our ABCs of NMOSD podcast series that is through a grant from VielaBio and talks about specific issues within NMOSD. We also have a magazine that comes out usually three times a year that gives the latest information about our organization, events, research. The same thing with our blog. We have a weekly blog that also kind of gives this up-to-date information about what we're doing and what we're up to.

[00:02:53] And then we have our family camp that happens every year. It brings families together who are affected by these rare neuroimmune disorders, and it's also an opportunity to connect with medical professionals. And so, you know, we unfortunately had to have ours virtually this year, but it's usually a really good opportunity to have all these families together and interact and, and learn

from one another, and also just have fun as well. Jeremy has been to camp many times, so you may recognize him from there as well.

[00:03:21] We also provide support to our-members through Walk-Run-N-Rolls. Jeremy again also works on that. They're organized by community members and are a way to raise awareness. They help us fund education and research opportunities, and of course, inform the local community about these disorders. We also collaborate and have partnerships with other organizations, many of which you can see in the expo booth here, so make sure you go and connect with them. It helps us increase awareness and also, you know, we like working with people who are doing, you know, work within, in the field so we're very, very lucky to have some amazing partners.

[00:03:57] We also have our Myelitis Helpline, which is an online resource that allows you to ask questions and gives you answers, and then if your question isn't answered, you can always submit a question that we will respond to personally. We also have an international support group network throughout the country, and then also throughout the world. That information is available on our website, and we also do support through phone calls and emails. We often get phone calls from individual people and chat with them on the phone or, or directly via email, so you can always reach us that way as well. And then we also launched a physician support portal for community physicians who are seeing patients with AFM. If they want to connect with a medical professional with expertise in AFM, they're able to submit a question via this support portal that we have here.

[00:04:52] And then as I said, we also do research and training. I will talk a little bit about the research that we've done very briefly. So CAPTURE was a, it's still ongoing, but it's a multicenter pediatric transverse myelitis and acute flaccid myelitis study that was led by Dr. Benjamin Greenberg and it was the first to combine assessments from healthcare providers and patients, and relate these two outcomes. And the study included a survey at three months, six months, and then 12 months after diagnosis, and now we will continue CAPTURE, with follow-up now every four months until 2026, which is really exciting because that's, you know, potentially over 10 years of data on outcomes for kids with AFM and TM.

[00:05:40] We also have our SRNA registry, so, this is a... anyone can participate.-So if you're interested, go on our website. It asks questions about diagnosis, treatments you may have received, how you're doing now,-and so it's an opportunity there to participate in research and contributes to our knowledge about these disorders. We also have a... we had a study about experiences with vaccinations. We're currently doing the data analysis for this, but our goal was really to understand and learn from our community about their experiences with vaccinations after their rare neuroimmune disorder diagnosis. And so we will report the results from that as soon as they are available. And then we've recently launched a COVID-19 survey, so if you're interested in participating, please reach out. Basically we want to learn about your experiences during this pandemic and see kind of how we can best support our community.

[00:06:37] And then, of course, we have our James T. Lubin Fellowship Award. Dr. Galli was one of our James T. Lubin Fellows. It supports the post residency training of clinicians after their neurology residency who want to specialize in these disorders.

[00:06:53] So with that, I'm going to turn it over to Jeremy.

**Jeremy Bennett:** [00:06:56] Hello. Thanks for being here today, everybody. As you may know, our organization was volunteer led for nearly 20 years, and volunteers are still the backbone of much of what we do. Our volunteers play an important role in how we connect and care for our members. Rare neuroimmune disorders are exactly that, rare. If you take a second to think about your own experience and what it was like in the beginning of your diagnosis I know, for me, I felt alone and scared, and I had a lot of questions. And that experience is not unique. But it is what had led me, and people like Sandy and Pauline and countless others, to get involved. We never want anyone to feel that way.

[00:07:47] And throughout the day, you've heard from some of our amazing medical professionals about how they can help people like you through diagnostics, treatments, research. You've just heard from GG about how SRNA helps you through programs like Ask the Expert podcasts, our Quality of Life Family Camp, the symposium and our fellowship program. Now I get to do something cool, and sort of flip the script on this and talk about how some of you have helped us.

[00:08:18] The SRNA Distinguished Service Award is an opportunity for us to shine a light on our volunteers and recognize them for their passion. Volunteerism empowers individuals to find their purpose and create meaningful change. The tireless advocates spend hours outside of their job and away from their families. They make phone calls, they answer emails from people in need, they reach out to their friends and neighbors for sponsorships and donations, and above all else, they work to create a strong community for everyone affected by rare neuroimmune disorders.

[00:08:51] Earlier this year, we asked for nominations for this award from our members. We wanted to hear from you about which SRNA volunteer made a difference in your life. As responses came in, we established a panel to decide a quote unquote winner, but in the end, this just really isn't about one person. Each volunteer brings something notable, something that our organization needed, something that changed someone's life, and really, how do you determine that value? So the decision was made to recognize all those that were nominated that met the established criteria.

[00:09:27] So it gives me the utmost honor to announce the recipients of our 2019 SRNA Distinguished Service Award. Janelle Healy and Jay Hewett, Barbara Nichols, Laura Martin, the MOG Project, including Julie Lefelar, Peter Fontanez, Andrea Mitchell, and Cynthia Albright, and our friends in Arizona, Gail Buch, Kate Krietor, Julie Barry, Barbara Sattler, and Kimberly Mazur. I could spend the next hour, talking to you all about each of these people and their impact, but unfortunately, I only have a couple of minutes left, so, we are doing a blog next week that will go into great detail about each of these deserving volunteers, so I implore you to please look for that and read about each of these awesome people.

[00:10:18] I do just want to give a quick rundown before we move over to the networking part of our program. Janelle and Jay are support group leaders in Southern California. Janelle has a TM diagnosis and she and Jay have been all in from the day that I met them. Barbara Nichols is a support group leader in the Dallas area. Barbara is basically getting a lifetime achievement award here. She was the first volunteer I met when I started here, which has been three years now, and is still as dedicated to

our community as ever. She has support group meetings, she participates in patient advocacy panels, and just so much more. Laura has spent countless hours contributing to the look and feel of this organization. She creates all the beautiful illustrations that you see on our website and our communications.

[00:11:08] The MOG Project, which you've seen here today, Julie came to us in 2018 with a goal to bring awareness to this new disorder, myelin oligodendrocyte glycoprotein-antibody-associated disease. Since then, she and her fellow volunteers have made a huge difference in the world of MOG and SRNA in general. They've done two Walk-Run-N-Rolls, and they've done other fundraisers as well. And our Arizona members, Gail, Kate, Julie, Barbara, and Kim. In 2019, these five volunteers put together their second Walk-Run-N-Roll, started a new support group, and created a partnership with Barrow Neurological Institute, that has increased our reach.-And one last thing. I think a different kind of congratulations is in order here, as it is my understanding that Janelle and Jay got engaged recently, and so I just really wanted to say congratulations to them, and then another thank you for all of our award winners.

[00:12:09] And now, we need to go over to the networking session where you're going to go there and be randomly selected to talk to another person. So this is really cool. This is a new thing we're doing. I'm going to head over there. GG, you're going? Yeah, everybody, so we'll just see what happens. Hopefully I'll see somebody there and we'll have a chat. Thanks so much, and we're only like a minute over, so let's go.

**GG deFiebre:** [00:12:47] Yep, we'll see everyone there, and then be back for the next talk. All right. Thank you all.

**Jeremy Bennett:** [00:12:52] Thanks everybody.