

Meet SRNA

You can view this presentation at: youtu.be/s5gzkCLOjok

[00:00:00] **Roberta Pesce:** Hello, everyone, and welcome back to the stage area. We hope you had a very good first session with the respective track that you are on. And I am joined now by GG deFiebre, my colleague and the Director of Research and Programs at SRNA. Hi, GG, over to you.

[00:00:27] **GG deFiebre:** Thank you. And thank you, everyone, for joining us today. I ... Yep, there we go. There are my slides. So, sorry we are meeting virtually, but we hope to be able to meet in person at some point soon. But we are happy to offer this symposium to everyone from across the world virtually. So, I'm going to start by just giving kind of a brief overview of the work that we do as SRNA.

[00:00:52] We are an organization that was founded in 1994. You may have known us previously as the Transverse Myelitis Association. We changed our name in 2019 to better reflect the work we do. We work with more than just people with transverse myelitis, so all of the rare neuroimmune disorders. We're a team of 11 people, and we support over 15,000 people from over 100 countries throughout the world.

[00:01:15] So, we are an international organization, as well. These are just some of... These are the 11 people I just mentioned who work hard on providing these programs and resources, as well as our amazing volunteers and support group leaders that we have. But if you see any of these faces in the chat or anything like that, please feel free to reach out with any questions or anything about SRNA or the symposium.

[00:01:43] So, as an organization, we advocate, support, and educate for people with rare neuroimmune disorders. These include ADEM, AFM, MOG antibody disease, NMOSD, optic neuritis, and TM. And we accelerate and invest in scientific research, as well as therapy development, and we also train clinician-scientists who work with people with these disorders. And our goal is to improve the quality of life of individuals with rare neuroimmune disorders and find a cure for these disorders, as well. And so, we do this through three different strategies that we call connect, care, cure.

[00:02:19] So, I'm going to talk a little bit about how we do this under our kind of umbrella of connect. So, our community members host Walk-Run-N-Rolls which are awareness events as well as fundraising events for people to meet in their local community. It's an opportunity to meet others with rare neuroimmune disorders, raise awareness in the local community, and also help fund research and education programs.

[00:02:46] We also have an amazing support group network that is run by our wonderful support group leaders throughout the country and world. We're also currently working on our peer-to-peer mentoring program which will provide one-on-one connections for people with rare neuroimmune disorders with a peer mentor. As a team, we also provide personalized support through phone calls and emails with our community.

[00:03:12] So, if you call us or email us, one of our staff members will reach out and talk to you, whether you're just newly diagnosed or just trying to find a physician in your area or have questions about symptom management. That's what we're here for, as well. Also, under the umbrella of connect, we have our blogs and magazines. So, you can see on the right there, we have our... an image of our magazine that we now offer online. We have weekly blogs that we send out via email and are posted on our website, and a magazine we usually do about two or three times a year.

[00:03:44] And these publications include stories from our members, research summaries about new research, different announcements, information about events, and other information. And you can subscribe to either of these on our website and get updates via email. Another way we connect with our community is through our family camp, and so normally we do this in person at the Center for Courageous Kids. Unfortunately, we haven't been able to meet in person due to COVID, but camp is a really wonderful opportunity to bring families together who have been impacted by one of the rare neuroimmune disorders.

[00:04:17] We also invite medical professionals who focus on these disorders, and it provides a really good opportunity for families to connect with one another and with these medical professionals and for kids to participate in these different sort of activities, like bowling for example. It's a really great opportunity. We hope to be back in person soon. We also, on our website, have our Hope Ambassador Program and stories.

[00:04:42] So, anyone can submit stories about their experience with one of these disorders, and you can go there and read other stories, as well, about people's experiences with their diagnosis and how they're doing now. And we also collaborate and partner with other organizations, and so you'll hear from our partners, as well, about how we do this with our nonprofits, other patient advocacy organizations, as well. And this helps us increase awareness and support opportunities for our community. We also provide our Myelitis Helpline which is an online tool.

[00:05:16] You can go there and ask questions about your diagnosis, about symptom management, finding resources. It helps kind of sort that information for you and direct you to areas on our website where you can find additional information. One of those places on our website where you can find a ton of information is our Resource Library. We have over 500 resources. This includes videos, podcasts, article summaries. You can sort by the disorder to get information or the type of resource that you want.

[00:05:45] So, you can sort by podcasts or videos, and it's... We are constantly updating it and adding new resources to the Resource Library. And then, of course we also have our symposiums. So, everyone here is currently attending our symposium, but our goal for the rare neuroimmune disorder symposium that we host yearly or every other year is to talk about the biology of these disorders, their causes, how to manage symptoms and then, of course, give our community information about resources... I mean about research and study opportunities, as well.

[00:06:19] And then, also kind of under the... So, I talked about connect and then a bit about the different things that we do under care. Another aspect of this is our information sheet. So, we have disorder information sheets for every single one of the rare neuroimmune disorders. I just put an example here with ADEM. But they're all available on our website for free. You can download and print them. They're also reviewed by members of our Medical and Scientific Council for accuracy. We try to update them as often as needed.

[00:06:48] We also have multiple podcast series. So, I'll talk about this one first. This is our "ABCs of NMOSD" podcast series that we do in collaboration with the Sumaira Foundation for NMO, the Connor B. Judge Foundation, and the Guthy-Jackson Charitable Foundation. So, it's a podcast series devoted just to NMOSD, learning about patient stories, how to manage symptoms, and about the biology of NMOSD.

[00:07:15] And so, we're grateful to the support from Horizon Therapeutics for this particular podcast series. We also have online our Medical Professional Network. So, this allows anyone to go on and look and search for a medical provider in their area that specializes in these rare neuroimmune disorders, because we know how difficult it can be to find someone who knows about them, especially with a rare condition. So, you're able to go there and search in your local area for a clinician that knows about these rare neuroimmune disorders.

[00:07:46] And so, in addition to our "ABCs of NMOSD" podcast series, we have our "Ask the Expert" podcast series which focuses on all the rare neuroimmune disorders, and we have different kind of branches of them, as well. So, we have our research edition, where we interview researchers about their current research or stuff that they've published.

[00:08:04] And then, also, we try quickly to add some resources on COVID and coronavirus when this kind of started affecting all of us last year. So, we have several that are focused on vaccinations and COVID kind of more broadly. In addition, we have our AFM Physician Consult and Support Portal. This provides physician-to-physician consults for anyone who suspects an AFM diagnosis. So, a physician can reach out, and they get a response within 24 hours from one of our experts from UT Southwestern or Johns Hopkins.

[00:08:37] And then, lastly, our last kind of umbrella is cure. So, we do this through advancing research to understand these disorders. And so, we fund research, and we also conduct research, and I'll be giving additional information about some of the research we've conducted on Sunday. So, I won't talk about that much right now. But we've also participated in the CAPTURE study which was a pediatric TM and AFM study.

[00:09:01] And if you go to the next slide, we also fund our James T. Lubin Fellowship award, which gives funding for fellows who are focused on treating and researching these disorders, as well, so you'll hear from several of them throughout the symposium. So, yeah, so thank you very much. And if you have any questions, please feel free to reach out to any one of us at SRNA.

[00:09:27] **Roberta Pesce:** Thank you so much, GG. I appreciate it. And to all of the other people watching us now, you can go back to the sessions area, where a lot of talks will be happening as we speak. So, enjoy yourselves, and we'll see you soon. Bye, everyone.