What's new at SRNA

Programs and events

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

[00:00:00] **Dr. GG deFiebre:** Hi everyone. My name is GG deFiebre. I'm Director of Research and Programs at SRNA. I'm sorry I can't be there in person with you, but I'm excited to see the recordings and hope you're all having a very good and informative time. I'm sure you know who SRNA is. As an organization we advocate for support and educate individuals and their families diagnosed with a spectrum of rare neuro immune disorders.

[00:00:34] This includes ADEM, AFM, MOGAD, NMOSD, ON, and TM. And we also accelerate and invest in scientific research, therapy development and the training of clinician scientists who are dedicated to these disorders. So, our end goal is to improve the quality of life of people with rare neuro immune disorders.

[00:00:55] As an organization, we were founded in 1994 as the Transverse Myelitis Association. And so, we were founded by families and individuals who were impacted by transverse myelitis. But as time went on, people were still reaching out to us talking about how they had an attack of optic neuritis or were told they had Devics disease or maybe diagnosed with ADEM.

[00:01:19] And so we always had an open arm, open arms policy on supporting individuals with these rare neuro immune disorders. So, in 2019, we actually changed our name to the Siegal Rare Neuroimmune Association or SRNA to better reflect the fact that we advocate for more than just transverse myelitis.

[00:01:41] And also to honor two of our founders Sandy and Pauline Siegel. We are a team of eight staff, some of whom are there today. And we support over 15,000 people from over 121 countries. We offer a membership as an organization, it's completely free. You could just go on, join, and it's the best way to stay in touch about events, information, new research opportunities and things like that.

[00:02:12] So if you're not already a member, I certainly encourage you to become one. And in 2024, we had about 500 new members joined, and these are people diagnosed with the rare neuro immune disorders, their relatives, care partners, as well as healthcare professionals and others who have an interest in this cause.

[00:02:34] So we are, if you look at our logo, there's three overlapping circles and those represent Connect, Care, and Cure, or the three Cs. So, I'm gonna talk a little bit about each of them and how they relate to the services and programs we provide. So, in terms of Connect, we have a wonderful support group network.

[00:02:56] We have several support group leaders throughout the country and world who offer support group meetings, both in person and virtually. And then we also have our peer-to-peer program. This is for someone who maybe doesn't wanna be in that support group setting but still wants support from someone who understands what they're going through.

[00:03:17] So you fill out a form and then get connected to a peer connect leader. And so that's again, for someone who maybe doesn't want to be in that group setting but wants more of that one-on-one interaction. We also offer personalized support through phone calls and emails. This is all based on what Sandy and Pauline did in the early days of, at the time, the TMA where they answered the phone in their kitchen and spoke to people who were reaching out for information about their diagnosis, how to find a doctor, all that.

[00:03:52] So that, that still remains a core piece of what we do as an organization. All right. And then online you can see and everything I'm talking about is also available on our website, so I certainly encourage you to check that out and learn more there. We have weekly blog posts, so you can subscribe to that to get that via email.

[00:04:16] And we also have a quarterly magazine. So, this is released obviously four times a year. And these include stories from members, research summaries, announcements about things that are happening, event recaps and other information. And again, you can subscribe via email to both of these. We also have our SRNA Quality of Life Family Camp.

[00:04:39] This is a really wonderful opportunity where we bring families affected by rare neuro immune disorders together and connect them with medical professionals. So, a child is diagnosed with one of these disorders. They get to go to camp. It's a fully accessible camp. Siblings are able to come and they're able to connect with peers who are going through the similar things.

[00:05:00] And the past few years we've held camp at Morgan's Camp in San Antonio, Texas. And as I said, it's a fully accessible camp. So, it provides all the fun opportunities that aren't available at a regular camp but allows children to be able to participate in ways that they might not at just your standard camp.

[00:05:22] And there's the dates for our next camp, our camp next year is available on our website, so check that out. And applications will be announced soon. We also have our Hope Ambassador Network. This is a bunch of stories from people who are diagnosed with rare neuro immune disorders that are available online.

[00:05:45] And then in terms of connect, we also collaborate and partner with other organizations to increase awareness and support opportunities. And of course, some of those organizations are represented in the expo area. So please make sure to go check them out. We also have our Walk-Run-N-Rolls. These are community events that are organized by volunteers.

[00:06:08] They're used to raise awareness, fund education and research opportunities, and also inform the local community. We have several Walk-Run-N-Rolls coming up in October. They're all listed on our website, so I encourage you to check them out there, but also talk to Lydia about that. And if you're interested in hosting one there's information on our website as well.

[00:06:31] And you can also chat with Lydia about that. Moving on to Care. So, we just talked about Connect. Now we're moving on to Care. In terms of care, our website is a very extensive source of information on rare neuro immune disorders. It was established in 1997 and has information from about diagnosis to treatment to ongoing care.

[00:06:55] And so I definitely encourage you to go there, look through what we have available. There is a lot! Included on our website is our resource library, where we have over 800 resources available. These include things like podcasts, symposium videos, information sheets and you can sort by, so you can look for resources based on the topic.

[00:07:19] So if you wanna look for bladder and bowel dysfunction or spasticity, you can look for those or the type of resource. So, if you're more of a podcast person, you can look for those. If you're into videos more, you can look for those. Or you can also look by disorder or find resources by disorder. But a lot of our resources are disorder agnostic, so I definitely encourage you to look not just at ones related to your disorder as many of the symptom management strategies and other things are the same.

[00:07:49] So there's a lot of resources there. We also have our myelitis helpline, which is an online tool that's there to help answer your questions about our organization as well as rare neuro immune disorders. And if your question isn't answered, there is the opportunity to be able to send us a question directly that we answer personally.

[00:08:08] We also have our symposiums. You are all at a symposium right now. But our first international symposium was held in 1999 with more than a hundred attendees from all over the world. And since then, we do a yearly symposium. So, we alternate between one national or international one that's a three-day symposium and then a regional symposium, like the one you are all currently at now, every other year.

[00:08:36] And all of the videos from this symposium as well as the symposium, as well as prior ones are available on our website. We also have our online learning portal. This has several courses that are tailored specifically for people with rare neuro immune disorders. It's self-paced.

[00:08:58] You can go on and learn at the pace you want to learn at. And there's one that's an overview of rare neuro immune disorders and then ones that are specific to each of the disorders. And then we're developing more as well, that should be released soon. And then we also have disorder information sheets available on our website.

[00:09:18] These talk in depth about each of the disorders. And then we also have our podcast series. This is called SRNA Sound Waves. It's our big broad name for it, but they're available anywhere you look for podcasts. So, Spotify, Apple Podcasts, and our website and YouTube. We also have a medical professional network where you can look for medical professionals in your area.

[00:09:43] Then we also have our Centers of Excellence in Rare Neuroimmune Disorders designation, which recognizes medical centers that provide care to those with rare neuro immune disorders. So, we have 17 centers. Emory and Children's CHOA are one of our CERNDs. So, you can learn more about them on our website.

[00:10:02] We also have, I'm just looking at the time, I just wanna make sure that I stay on time here. But we do have a physician consult and support portal where if clinicians have seen a patient that they maybe are not sure how to diagnose or manage moving forward, or maybe someone that's not as knowledgeable about rare neuro immune disorders.

[00:10:27] They can fill out a form and then get matched to an expert in these disorders. And they do a physician to physician consult that way. And then lastly, our last C, Cure. We have the Eclipse fund, which is, was started in memory of Pauline Siegel. Pauline again was one of our founding members, and she unfortunately passed away several years ago.

[00:10:53] So this research fund was created in memory and in her honor. As part of this, we accelerate research to advance our understanding of rare neuro immune disorders. And we've done several SRNA-initiated research projects as well as we provide research grants to our CERND network. So, our registry is available online.

[00:11:22] We have 763 participants who've filled out the registry survey so far. You can go on, it takes about an hour, but you fill out information about before your diagnosis, your diagnosis process, what treatments you received, and how you're doing now. And then we send out updates yearly so that we can, we send out a survey yearly so we can get updates on how you're doing now.

[00:11:46] We also have our James T. Lubin Clinician Scientist Fellowship Award. This is a post-residency fellowship for clinicians who are interested in focusing on rare neuro immune disorders. We've funded 10 fellows since 2012 and have seven training institutions. And on our website in the, under the James T. Lubin Fellowship page, there's a really wonderful video that talks about the fellowship and the impact of the fellowship, and you actually hear from some of the mentors as well as the former fellows about the impact of the fellowship.

[00:12:26] Our current fellows are Dr. Sidney Lee at the University of Utah, and Dr. Rachel Walsh at Boston Children's Hospital. And we just closed our application for next year's fellow. So, we will announce information about them at a later date. And then if you have any questions, feel free to ask any of the SRNA staff members who are there today.

[00:12:49] And you can also always email us at info@wearesrna.org or fill out the contact page on our website, and we will get back to you with any of the questions that you might have.