

# SRNA Research Updates

## Registry, Vaccination Study, and COVID-19 Study

You can view this presentation at: [youtu.be/GjN3QdqZzKs](https://youtu.be/GjN3QdqZzKs)

[00:00:00] **Roberta Pesce:** For all of those who are listening, did you know that we conduct research at SRNA? I am very excited to be joined by GG deFiebre, Director of Research and Programs at SRNA, to tell you a little bit more about our ongoing efforts, our recently completed research studies, and some of our findings. So hi, GG, over to you.

[00:00:27] **GG deFiebre:** Hello. Thank you. Thank you so much and thank you everyone for sticking with us for day three of this symposium. I apologize in advance, I have a cat right next to me, so if he appears, that's what happens when you're at home. So, we at SRNA know how important research is for improving the quality of life of our community. And throughout all of our work research remains a top commitment for us as an organization. And so, we fund research, but we also conduct our own research, and we do this work through the Pauline H. Siegel Eclipse Fund for research.

[00:01:02] And so Pauline Siegel was diagnosed with transverse myelitis and was one of the founders of the Transverse Myelitis Association then, the now SRNA. And when she unfortunately passed away the association created this fund for research in her honor. And so, we continue doing research through this fund. And so, some of what I'm about to say is some of the research we've conducted. It's very kind of top-level summaries of some of the research we've done, I hope to add some point soon give you all a kind of deeper dive into the information we have gained from your participation in the surveys that we've sent out.

[00:01:45] So as discussed yesterday, vaccinations are really, I'd say we get a ton of questions about vaccines and whether people should get vaccinations or not, especially with COVID-19, we've gotten a ton of questions about vaccinations for those with rare neuroimmune disorders. And as also talked about by doctors Levy, Greenberg, and Pardo, it's really hard to talk about kind of causality with vaccines. So, we know that sometimes with vaccines someone will get a vaccination and then will go on to have an onset of one of these disorders because proving that causation is really difficult.

[00:02:21] And so our goal with this study isn't really to look at that potential causation or any of that, it's more to just really understand from our community what their experience is with receiving vaccinations have been kind of before their diagnosis and then now after their diagnosis, really with the focus on what their experience

has been after their diagnosis. Are they getting vaccines? What are their physicians recommending? And if they are getting vaccinations, what has their experience been like?

[00:02:52] So we selected 600 people from our membership database randomly and sent them a survey through SurveyMonkey, which is an online survey tool and through a hard copy survey through postal mail. And so, of the 600 we randomly selected, 223 completed the survey. We asked about people's experiences with vaccinations, and for anyone who said that they had another attack or a second, or third, or fourth attack within 30 days of receiving a vaccine after their onset, we asked them to participate in an interviewer administered questionnaire over the phone so we can get a little bit more information about what happened there. So, thank you to everyone who participated in this study. Some of you might be listening today, we really appreciate the time you took to do that.

[00:03:44] So in terms of respondents, about 74 percent had a diagnosis of TM, 15 percent with NMOSD, and then we did have respondents who had a diagnosis of ADEM, AFM, MOGAD, and then also recurrent TM as well. And so, we asked people whether they had a vaccination within 30 days before their onset. So about 16 percent of people who responded to the survey said that they had a vaccine and then had their onset within 30 days of that. And then of these people, 13 of them went on to get another vaccine at some point after their onset and none of them had another attack again within 30 days of the vaccine.

[00:04:28] And then we asked people, "Since your onset, since your diagnosis have you gotten any vaccinations?" And about 65 percent said that they did get one or more after their disease onset. And I imagine that this, we collected these data before the COVID-19 pandemic, I imagine this number would probably be higher now at this point just based on the conversations I've been having with members of our community.

[00:04:51] So as I said, we asked anyone who said that they had a vaccination and then another attack after their onset. We invited them to participate in a phone interview where we asked some additional questions. And so, we had six people say that they had a vaccination and then another attack, so it was about four percent of those who said that they had this second, or third, or fourth attack.

[00:05:17] And so we reached out to all six of them, we got in contact with three of them. Of the three that didn't respond to our outreach, two of them had a diagnosis of TM, but they were unsure of their antibody status, so they didn't know whether they were positive for aquaporin-4, and one had NMOSD. And then of the three we were able to talk to, two of them had TM, but were again unsure of their aquaporin-4 antibody status, and they were also unsure if new inflammation was confirmed on imaging. So, they didn't know. We had a conversation on Friday about the difference between a relapse and pseudo relapse, so new inflammation versus just kind of an old worsening of symptoms without new inflammation. So, the people we talked to weren't sure whether they had new inflammation with this subsequent attack. And then one of them was aquaporin-4 positive. And then of the three that we talked to, two ended up getting a flu vaccine again later with no additional issues.

[00:06:18] So really, overall kind of the big picture kind of take on this is that in the participants who were known to be aquaporin-4, so monophasic TM, there were no post-vaccine recurrent inflammatory events, and this kind of mirrors what Dr. Greenberg said that he's never had in his experience, one of his patients with monophasic TM go on to have another attack post-vaccine.

[00:06:45] But we also found that many people were unsure about their diagnosis, so they didn't know necessarily their diagnosis. They didn't know whether they had been tested for aquaporin-4 or the MOG antibodies, or if they had it and didn't know if they were positive or not. And again, there was a lot of confusion about the

idea of a relapse versus a pseudo relapse, so whether there was new inflammation or not or just kind of a worsening of symptoms. So definitely we hope that people have learned also from this symposium and have a better understanding of the difference between these two things.

[00:07:16] And it's possible, again, this was self-reported, we didn't confirm these findings with medical records. It's possible that those who had another attack after a vaccine were more likely to respond to the survey, so it's possible that these findings were biased towards overestimating the risk of an inflammatory attack after a vaccine, as they were more likely potentially to respond.

[00:07:39] And then in terms of those who didn't get a vaccination after their onset, which is a little less than half, of those people about half said that their healthcare provider told them not to get a vaccination because of their rare neuroimmune disorder. Again, we hear that a lot, people say, "My doctor told me never to get another vaccine again," even though that might necessarily be evidence-based. So, it's important that we know that information that physicians are potentially telling their patients that.

[00:08:05] More than a third said that they didn't want to receive vaccinations because they were concerned there were problems with their immune system kind of more broadly, and then about a third said they didn't want to receive vaccinations because they believed a vaccine caused their disorder. So again, this is kind of a very brief overview, and we will provide additional information soon on this research.

[00:08:23] We also have a registry. So, this is again a survey you can take online. And the registry, our goal is to advance research, collaborate with researchers around the world, and then also help identify participants for clinical trials. And so, of the people who responded to the survey so far, as of March, there were 531, we've had a little bit more since then.

[00:08:44] And so we've got people with all of the disorders who have participated. And then we found that about 37 percent were diagnosed less than a week after symptom onset, but for about 31 percent of respondents, it took longer than 6 weeks to be diagnosed. And we know how important a quick and accurate diagnosis and then treatment is for potential kind of long-term outcomes. So, the fact that it took longer than 6 weeks to be diagnosed is definitely an issue, and I imagine this also differs based on when people were diagnosed. So, if they were diagnosed 20 years ago, versus 10 years ago versus last year, hopefully that time frame has dropped a bit.

[00:09:19] And then less than a third of participants received second acute treatment during their initial attack. So, Dr. Flanagan talked about the different treatments, so what we found is that less than a third of people got a second acute treatment, so they have just gotten IV steroids and not plasma exchange or IVIG.

[00:09:39] And then overall, about 83 percent received treatments after their diagnosis, with 17 percent not receiving treatment. And then in terms of symptoms like people were currently experiencing, about 80 percent said that they had some sort of loss of sensation post diagnosis, some weakness or paralysis. We also found that about 77 percent had neuropathic pain currently, bladder and bowel dysfunction as well, some spasticity. About 63 percent reported that they were currently experiencing spasticity. And then about 80 percent said that they received rehabilitation after their diagnosis.

[00:10:22] And so how to participate? So, you are able to go on our website and participate in this research. So, you must be an adult, or if you are a child, if you are participating on behalf of a child, you can do that as a parent, but the child if they're over the age of 7, 7 or older, they have to provide consent as well. It's a voluntary registry and I am going to show you how to do it here.

[00:10:49] So you can go to our website, the URL is there. You go there, review the consent form, see what it is you're participating in. Fill out that interest form where it says join now, and then you'll get a survey sent directly to your e-mail. And so, you don't have to go to a medical center to do this, this is through our website directly, and it's a survey that you fill out on your own.

[00:11:13] And so one last thing very quickly, in response to the COVID-19 pandemic we wanted to find out how the pandemic was impacting our community, whether it was impacting accessing healthcare, whether there was any potential social challenges like job loss or issues with accessing medication or other supplies. And so, we really want to know because it's important for us to create programs or educational materials for our community and for the medical community about how the pandemic is impacting our community.

[00:11:46] And so this involved a survey that was done over a phone that an interviewer guided participants through. And so very briefly again this is, we'll do a kind of bigger, broader, more in-depth analysis at some point soon, but about 55 percent were not employed before the pandemic. Unfortunately, about 14 percent were unfortunately let go from their jobs due to the pandemic, again this isn't isolated to our community, but an issue that has occurred kind of broadly.

[00:12:12] Eighty percent of people had visits that were shifted to virtual visits, which can be good and bad. About half had issues accessing medical care in some way. And then thankfully only about five percent had a COVID-19 diagnosis, and thankfully none of them were hospitalized, so we did ask about that as well. So that is the end of my presentation. I think I did it right on time too.

[00:12:38] **Roberta Pesce:** You did. You did perfect. Yes, right on time. Thank you so much GG, this was great.

[00:12:45] **GG deFiebre:** Thank you.

[00:12:45] **Roberta Pesce:** We appreciate you being here. Thanks.