

## Welcome and Goals of the 2020 RNDS

You can listen to the audio of this talk at: <https://youtu.be/7nskTd3B32A>

**Sandy Siegel:** [00:00:00] Good morning. I'm Sandy Siegel, president of the Siegel Rare Neuroimmune Association. I want to welcome all of you to the 2020 Rare Neuroimmune Disorder Symposium. This symposium is being brought to you by the Siegel Rare Neuroimmune Association and the University of Utah.

[00:00:25] These education programs require so much planning and organizing, and I want to start out by thanking our Executive Director, Chitra Krishnan and our really exceptional staff, Krissy Dilger, Jeremy Bennett, Rebecca Whitney, GG deFiebre, and Roberta Pesce for all of the work that they've put in to putting this program together. And I also want to thank Linda Malecky and Debbie Capen from our Executive Committee. And you can visit with Debbie during the symposium, she will be in our exhibit area.

[00:01:09] We are proud of and grateful for our relationship with the University of Utah. They are one of our mentor institutions for the James T. Lubin Fellowship. So I want to especially thank Dr. Stacey Clardy, Dr. Jonathan Galli and Kaho Wong for their work on this symposium as well. I'm also going to thank our sponsors for helping to support this program, Alexion, Genentech, and Viela, Viela Bio, and our exhibitor, the Kennedy Krieger Institute. And finally I want to thank our partners, the Acute Flaccid Myelitis Association, the Connor B. Judge Foundation, the Guthy-Jackson Foundation, The MOG Project and The Sumaira Foundation.

[00:02:04] I usually start every symposium by thanking all of the attendees for making the effort to travel to an important education program. This year is so different for all of us in so many ways, so this year I'm going to thank all of you for figuring out how to get into Hopin, and for brushing your hair.

[00:02:28] It is a fact that you become the best advocate for your medical care by educating yourself. I know by the end of the day you will learn a great deal from all of the experts who so graciously give us their time and knowledge to help our community. And with that, I am going to turn it over to Dr. Jonathan Galli. Thank you, Dr. Galli. I'll turn it over to you.

**Dr. Jonathan Galli:** [00:02:57] Thank you, Sandy. Good morning, everybody. I hope you can all hear me. I think we're all adjusting to this virtual session. As Sandy said, I'm Doctor Jonathan Galli with the University of Utah, Department of Neurology. I'd like to thank everyone this morning for joining us at the 2020 Siegel Rare Neuroimmune Association Regional Symposium hosted from Salt Lake City.

[00:03:33] When we started organizing this meeting last year, we originally were planning on hosting this at our institution at the University of Utah in Salt Lake City. However, in these unprecedented times, we've had to learn to adapt. Like everyone since the beginning of COVID-19, a lot has changed

to our definition of normal. Despite these challenges, we hope to offer the best patient day possible for the members of the SRNA community.

[00:04:04] While this year, it's being held on a virtual platform, our guest speakers will still be able to share up-to-date information about rare neurological diseases that can better inform and empower our patients and families. In these difficult times, I have been trying to see a silver lining in things. While we're unable to meet in person this year, since we are holding this symposium on a virtual platform, we have been able to expand our speaker availability to many of our SRNA members and providers across the country, many of who you will meet today, along with my colleagues at the University of Utah.

[00:04:42] Before we start talking logistics and objectives for the day, I would like to share with you a little bit more about my experience working with SRNA and the experience that I have had since working with this wonderful group.

[00:04:56] Let's briefly rewind. I was in Burlington, Vermont for my undergraduate and medical school training, when I began to develop an interest in patients with autoimmune neurological conditions. And this really began after I took care of a patient with neuromyelitis optica, and later another patient with NMDA-receptor encephalitis. When eventually interviewing for residency training, I had the opportunity to meet Dr. Stacey Clardy, sort of by chance, who had just started an autoimmune neurology fellowship here at the University of Utah in Salt Lake. I took the opportunity to train in Salt Lake, really with hopes that I could eventually work under Dr. Clardy as her fellow.

[00:05:38] The University of Utah is a unique institution to train and practice at, due to its location in the Mountain West. We serve as a tertiary care center for many of the surrounding states, and this allows us to provide care for many patients with rare conditions including ADEM, transverse myelitis, neuromyelitis, and acute flaccid myelitis.

[00:05:58] Dr. Clardy eventually brought me on as a fellow, and at this point, we really focus on specialized training, within specific areas of neurology, and in this case, autoimmune neurology. And this is really where my relationship with SRNA began, and actually at that point we were known as the Transverse Myelitis Association, or TMA. Through the James T. Lubin Fellowship, SRNA helped to fund my fellowship experience. And this was really important as it gave me ample time in clinic to spend time with patients with rare autoimmune neurological conditions, learning from Dr. Clardy how to diagnose, treat and ultimately care for these patients over the long term. In addition, the generosity of SRNA allowed me to have protected time to work on several research projects, with focus on NMO in patients through the Department of Defense.

[00:06:53] And most importantly, my involvement through SRNA has provided me the wonderful opportunity to meet many of the patients and families involved with SRNA, both at the summer CCK, as well as the annual symposiums. And that's why, when SRNA approached us, myself and Dr. Clardy, about hosting the symposium, we jumped at this opportunity.

[00:07:02] Our meeting today is for you, our patients and our families. And our goals for today are relatively simple. First and foremost we want to provide the feeling of community as best we can at a virtual meeting. We want to provide you with the most up-to-date information on the diagnosis,

the research, treatment, and symptom management for those of you that are affected by ADEM, acute flaccid myelitis, transverse myelitis, optic neuritis, neuromyelitis, and MOG antibody mediated disease. We will spend the morning discussing each of these diagnoses in depth and then transition more to symptom management, closer to noon.

[00:07:58] This afternoon we will cover updates on rare neuroimmune disorders in this COVID-19 era. And we'll have discussions on the long-term immune therapies in these diseases. Later we will have breakout sessions where we will cover several topics including imaging findings in these conditions, managing stress, and discussing resources for school, as well as discussing the information regarding the new now FDA approved NMO treatments.

[00:08:28] Throughout the day we will have several breaks for everyone to recharge and hopefully connect with one another as best we can on a virtual platform. Many of you may have questions regarding your unique diagnosis or treatment plans that come up through the day. Please be aware that we will do our best to answer some of your questions. However, please know that we may not be able to weigh in specifically on your case or on your treatment plans and give medical advice as we are not your current care provider. However, that being said, we will do our best to clarify any questions that you have during our moderated question sessions, question and answer sessions later today.

[00:09:12] Lastly, I would like to thank everyone who has taken the time this weekend to be a part of this event, and that includes our patients and families who have taken the time this weekend to, as Sandy said, brush your hair and log on to Hopin, our speakers for taking the time to prepare their talks as well as join us on a Saturday, and the SRNA and University of Utah staff who, without them, today would not have happened, and they do so much work in the background, I can promise you that. And lastly, I'd like to thank our generous sponsors who include Alexion, Genentech, and Viela Bio. Please make sure to stop by all our sponsors' booths in the digital expo area to learn more about each one of them.

[00:10:01] And with that said, I probably talked too fast because we're ahead of schedule, but I think now we can get started on our day. Our first talk will be by my now colleague, who at one point was my fellow when I was a resident, Dr. Michael Sweeney, and he's going to be talking to us about acute flaccid myelitis.