

Welcome, Day 1

You can view this presentation at: youtu.be/JiA1QEXdLZU

[00:00:00] **Roberta Pesce:** Good morning, good afternoon, and good evening to all depending on where you are located, of course. We are incredibly excited that you are all here with us today for the 2021 RNDS. And before going into the official welcome, I really wanted to take a moment and make sure that you get the best out of this experience, and that you can use all of the features this platform, Hopin, offers.

[00:00:32] If you're with me today, it means that you have successfully entered the online event and that you have navigated to the stage area. It probably also means that you initially landed on the reception page, which is the page that we are looking at now. The reception page is a great page because as you can see, all of the info is right here. It's the same info that you saw in the registration page when you registered for the event, you can find back here - the sponsors, our schedule, also the speakers that will be giving their talks. It is really nice that you can filter based on the day.

[00:01:08] It's 3 days. We have a packed agenda, and you're able to search on a segment by keyword or by using filter options. Please make sure that you click on the 'view more' segments in order to see the full schedule for each day. To the right of this reception area, and I would say over the entire areas of the event, there is a section that contains other basic details about the RNDS and our events. The section will be, as I just mentioned, available in most areas, and you can access it at any time.

[00:01:45] You can see there is a little event tab here and then 'My Agenda' here. The 'My Agenda' is very helpful if you want to save certain items of the schedule or if you have a meeting scheduled you need to remember, for example. The chat options, the event chat is great. This is where you can introduce yourself, ask general questions about the events, make comments, and post messages at any time. And to the right of that you see a list of all the attendees. It's the 'people' tab. At any point during the RNDS, you can click on anyone you'd like and send them a message to chat, send a meeting invitation, or even invite them to a video chat.

[00:02:27] We wanted to make sure to keep the connections, and really the connection aspect that we hold so dear from our in-person events, alive. And we encourage you all to update your profile picture, add a little bio, and meet the community in between talks. It is a 3-day event, and we allocated specific times for you to mingle. We just think it's such an important part of what makes our events, our events. Please, please, please connect with one another and share information.

[00:03:03] Next, we move to the stage. I'm a little frightened to do so, because I will be seeing and hearing myself, but the stage is where most of our talks will take place. There is, obviously, in the stage area... Let me quickly try and do this without hearing myself. There we go. In the stage area, there will also be a chat function. As you can see, we're on the stage. There is a chat function where you can discuss the things that are being presented on stage.

[00:03:32] In addition to the chat, there is a Q and A panel which is where we encourage you to ask the questions pertinent to the talks that are happening. And we will ask the top-voted questions to our speakers at the end of each talk, so please make sure to ask all of the questions you have that pop in your head. This is the place. This is the place to ask them. We have such great experts. We have the best specialists in the field, so please ask your questions and they'll be happy to answer them.

[00:04:01] Next to the Q and A panel, we have a poll panel. During the event, we'll do our best to keep you engaged, excited, and overall, hopefully happy. And you can expect specific questions about how you're feeling about the conference and also some slightly more fun questions like, "What's your favorite horror movie?" We're in October after all. Or, "What's your favorite pizza topping?" We want you to learn this weekend, that's for sure, and connect, but also have a little bit of fun.

[00:04:34] Finally, another very important feature is the closed caption feature. During our RNDS, all of our talks and sessions will be transcribed live, and you can view real-time captions in the closed caption panel. They're available both in English and in Spanish. Next, we're going to move to the session area. You can think of sessions like breakout rooms. As you all know, this year, we've decided to have three different and concurrent tracks. One for those who have been recently diagnosed, one for those who were diagnosed more than 2 years ago, and one focused on pediatric care.

[00:05:11] This was based on the feedback that you gave us, and we really wanted to make sure to incorporate that in this year's event. All of these talks will be happening today, Friday, October 8th, and they will take place in this session area. Important to note is that the session will only appear in a session area at the exact time of the session. So, don't be alarmed if you enter the session and... if you enter the session area a minute before and your session doesn't show up. Refresh the browser at the right time and then you should be able to see it and you can enter the session and listen into the talk.

[00:05:57] Okay, this next part is going to be really fun. It is a networking session. We've heard, last year, from the people that have attended our conference last year that this was one of their favorite features. This is the feature that lets you match up randomly with other attendees for quick virtual connections.

[00:06:17] So, when you're ready, you click the 'join' button, and you will be randomly matched with someone else who's also waiting in this networking area. And once we're both on screen, you'll see a timer on the top right-hand corner that will tell you how much time is left. I believe it's 3 minutes. And after the 3 minutes, you'll be randomly assigned to another person. Important, don't panic if the 3 minutes are over. There is a connect button next to the timer. That basically, what it does, it allows you to exchange information between the two of you, just like a business card. And so, after you are done talking or when you have some free time, you're always able to connect with that person again because you have their contact details.

[00:07:04] So, these 3 minutes, they're 3 minutes that you're able to take the conversation somewhere else for a longer time once it's done. All right, finally, the expo session. The expo session, just like any physical event, you can visit the booths of our partners or collaborators if you are interested in learning more about

what they do. And when you click inside of a booth, you can see some information on the right-hand side. Sometimes there is a button to register your interest or linking to another web page. And in some booths, you'll even see a live person staffing the booth on screen, which is exciting because you can meet them.

[00:07:45] You can join the booth discussion by asking to share your audio and video, and once you're on the screen, everybody else in the booth can see you and hear you. And you're able to ask questions and engage with the people that are in the booth also. So, we really encourage you to do so. We have... Our community partners are here. Other organizations are here who are doing incredibly exciting things for all of the rare neuroimmune disorders that we advocate for, so we highly recommend you to check out the expo booth. We have allocated time for you to visit the expo booth as well in the connect and learn session, so please make sure to check it out.

[00:08:25] Finally, we have the replay section. The replay section is a great section for when you miss a talk or weren't able to attend. These things happen. It's 3 days, so we don't expect you to be here at all times every time. We record all of our talks, and they will become available soon after in this replay section so you're able to come back here and listen to the talk again, or if there's anything that you want to re-listen to because you listened to it earlier, but you forgot something or you wanted to check something, this is the place to be.

[00:08:57] All right, I think these were all of the basics. We really hope you enjoy this conference, you enjoy today, and that you overall just have a great time and learn a lot. Make sure to meet many new people. At any point in time, if you have any questions about how Hopin works, how the platform works, about a talk, you can reach out to us. The SRNA staff will be here at all times. You can search for us in the 'people' panel if you look for organizers, organizer, we should all show up and you can send us a message and reach out to us, so we're here. All right, I think I am done. I'll be back briefly in just a couple of minutes with the president, our president of SRNA, Sandy Siegel, to give the official welcome and kick us off this weekend. Thank you, all, so much and see you soon. Bye.

[00:10:15] Welcome back, everyone. I am now joined by Sandy Siegel, who will be officially kicking off our 2021 RNDS. Thank you, Sandy. Over to you.

[00:10:50] **Sandy Siegel, PhD:** Thank you, Roberta. Our first symposium was held in Seattle in 1999. Dr. Brian Weinshenker had recently completed his study on plasma exchange, and he made his first public presentation of the results. Dr. Douglas Kerr attended as he was completing his training at Johns Hopkins and decided to become the first TM specialist in the world and established the Center of Excellence. His first hire, supported by the Transverse Myelitis Association, was a research administrator. Her name was Chitra Krishnan, who has become the SRNA Executive Director.

[00:11:38] The education you will receive this weekend is so important. The emotional and social support for people with very rare disorders is also critically important, and we hope to meet next year in-person. I want to thank our cohosts, Massachusetts General Hospital, Harvard Medical School, NMO Clinic and Research Laboratory, Johns Hopkins Medicine and Johns Hopkins Myelitis Center and Myelopathy Center, UT Southwestern Medical Center, Children's Health, and CONQUER.

[00:12:13] I would also like to thank our sponsors, Alexion - AstraZeneca Rare Disease, Genentech, and Horizon Therapeutics. Thank you to our partner advocacy organizations for their participation, the Guthy-Jackson Charitable Foundation, the MOG Project, the Sumaira Foundation, the Acute Flaccid Myelitis Foundation, the Cody Unser First Step Foundation, and the Connor B. Judge Foundation.

[00:12:46] The physicians and researchers who will be presenting this weekend are among the experts in these rare neuroimmune disorders. We are grateful for the donation of their time and expertise in offering this education, as well as all of what they do for our community. I want to thank the SRNA staff for their hard work in putting together this symposium. Lydia, Angel, Krissy, Rebecca, GG, Roberta, and Chitra, we are so grateful for all of your hard work. I also want to thank our Executive Committee for the work that they generously donate as volunteers. Debbie, Jim, and Linda, thank you.

[00:13:33] Finally, I would like to thank all of you for being here. The downside of this virtual meeting is that I can't be with you this weekend. The upside is that people can attend from the more than 110 countries where our members live. The information you will receive this weekend is critical for your health and well-being. Pauline and I learned very early on that her quality of life was intimately connected to how much we understood about her disorder. I'm thrilled that you are here, and I hope that what you learn this weekend will make you the best advocate for your medical care. Thank you.

[00:14:20] **Roberta Pesce:** Thank you so much, Sandy. All right, I think that the 2021 RNDS has now officially begun. Please remain on the stage for a couple of more minutes as we will now start streaming our community's This Is Me stories. This Is Me is an awareness campaign that we have recently launched to challenge the social issues and understanding around rare diseases and disabilities. And by bringing our communities, your voice, to the forefront, we can empower researchers, physicians, and governing entities to understand these rare neuroimmune disorders better.

[00:14:56] Please watch these stories that are about to be streamed, and if you want to share your story, you can also do so. And please head to the SRNA's expo booth. We can answer any questions you have and give you more information on how to get involved. Also, remind you that our three educational tracks will start immediately after this, and all talks will take place at 12:30 PM Eastern Time in the sessions area. Thank you, all, and bye for now.

[00:15:24] **JCruz Gudino:** "Hi, my name is JCruz Gudino. I live in Sacramento, California. I'm 33 years old, and I was diagnosed with transverse myelitis January 25th, 2019. When I was first diagnosed with transverse myelitis, honestly, I did not know how to feel about it. I just remembered being in a hospital bed and just thinking of what I had to do next. I was just really in shock, I would say. But I somehow knew that it's going to get better, and that moment was going to be the worst state that I would be in, and then moving forward I would feel better.

[00:16:50] And I would say the reason I felt that way is because it's not like I knew what transverse myelitis really meant. Now, living with transverse myelitis for about, I would say, two and half years has really changed the way I look at planning my day, planning trips, going out to grocery stores, doing events, and, of course, how I approach training. I want to go and do the events, especially with my family. I have four little ones and with my wife. And I need to make sure that one, I have my therapeutics with me, equipment.

[00:17:30] If I travel short distance or long distance, I've got to have some form of my therapeutics with me. I need to make sure I know where all the bathrooms are because of the lack of bladder control. I need to make sure that I am well rested, figure out how long am I going to be sitting still, how long am I not going to be sitting still, and that really has become a little bit more natural now. At first, it was very overwhelming, but it's kind of like second nature now.

[00:18:00] In regards to my mental state, it's made me very mentally tough. It takes a lot to bring me down and now has honestly given me this strength I never knew I had and perseverance, endurance, and faith and

hoping and always looking at the brighter side on how my life can be a lot worse. The level of transverse myelitis that affected me is that I constantly need to keep my legs moving. The less active I am, the more my symptoms flare up, the more pain I'm in, the more my chronic pain increases.

[00:18:39] So, I literally have now been training every single day since transverse myelitis. When I take a day off, it's not fun. It hurts. It hurts really bad. When it comes to my interacting with family and friends, with my children, it's probably harder. It's harder with my younger ones, because they don't understand why sometimes I can't play with them. They don't fully understand why... my mom says like... My wife would say that "Daddy needs a break. Daddy needs to lay down. Daddy can't be touched." It's definitely very, very hard, and I do my best to make sure my children don't see me break down in the sense of emotionally.

[00:19:25] I believe at first glance, no one notices that I have transverse myelitis or have a form of disability. If I'm already standing and moving around, they don't really notice anything. It's typically when I'm sitting down, and I have to stand up. I'm very slow at getting up. Sometimes I stand up, and my muscles don't like it and they contract, and they pull me back to my seat. And it takes a while for my legs to get going, like warmed up. That would be the only time that someone might notice that I have a disability or transverse myelitis.

[00:20:04] I've been very grateful that other than that little visual cue, there's not really much that limits me from day-to-day activities, or I've done a really good job coping with it, that in my brain now, almost 3 years in, I guess is not really a limitation. I really don't know how to explain it. Like I mentioned, I'm pretty grateful that I don't have very many visual cues of displaying that I have an issue.

[00:20:40] It's only when I was having nerve pain or some muscle spasms that it will come up, because I'll get a really bad twitch or a really bad spasm associated with some nerve pain, and we're just sitting around the table, and this person that I'm talking to for the first time may not know what's going on. That's like honestly the only time I see it being introduced. But for meeting complete strangers, they wouldn't even know that I have a disease. My name is JCruz Gudino. I have transverse myelitis, and this is me."

[00:21:28] **Cassidy:** "Hi, I'm Cassidy. I am from Southeast Missouri, and I am MOG positive. I just turned 33 and have been MOG positive for the last approximately 2 years. I had my official diagnosis in April of 2018 and my first attack in January of 2018. I'll never forget what was going through my mind and what I was doing when my doctor walked in the ER and started talking to my dad and I as if he were fixing to admit us, and this eye pain wasn't just something that they could fix with some medicine or some antibiotics.

[00:22:13] It wasn't really anything to worry about. I had my newborn with me. I'll never forget that I was nursing him and just had this thought that as the doctor was telling me that they'll hospitalize me for approximately at least a week and that I'll be on high-dose steroids among other medicines as they try to either figure out or officially diagnosis me, that my whole world was changing. And it was changing in a way that nobody could have ever dreamed, nor would we have ever asked for.

[00:22:51] So, it was very overwhelming, and it was very frustrating waiting to find out all of the information. There's a long period of time as they rule stuff out that you're left to let your mind wander. I think some of the biggest changes that I found are fatigue, because it goes beyond just feeling tired. Sometimes the little thing makes my arms or my hands or my fingers feel like folding this blanket weighs 100 pounds and I'm never going to get it folded and I'm so tired that I have to go sit down and stop working for a bit because I just can't stand it.

[00:23:29] I've been lucky. I have, again, been blessed that nobody has made me feel different. I have fought

the good fight for numerous groups and causes in my area and have been very blessed to have that support returned to me and not made me feel like when I need to hit pause or I need to stop doing something for a little bit, that I'm shamed or that I don't have the support that I need. My family, my friends, my coworkers, I'm just very blessed by the people that I have in my life and that they have been such great support and encouragement for me during this period. It's been challenging, but I've made it through. My name is Cassidy and I have MOGAD, and this is me."