Welcome

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Sandy Siegel: [00:00:04] Wonderful to see so many familiar faces out there. Welcome to the 2022 RNDS which is being hosted by the Siegel Rare Neuroimmune Association, Massachusetts General, UT Southwestern, Johns Hopkins, Children's Health Medical Center, and the Conquer Project. This is truly a collaborative effort as is almost everything that our association does. I also want to thank the sponsors who have made this symposium possible, Alexion, Genentech, and Horizon, thank you so much for your support. This is such a critical endeavor for our community, and we appreciate your involvement and your support in all of this. I would also like to thank our partners, the Guthy-Jackson Foundation, the MOG Project, and the Sumaira Foundation.

[00:01:25] When Pauline and I first got the association going, which in those days was the Transverse Myelitis Association because in 1994 we only knew about transverse myelitis. We knew the importance of education for our community, and we learned it firsthand because when Pauline was diagnosed with transverse myelitis, we knew absolutely nothing about what happened to her. I can remember very vividly going to the medical library at Ohio State University because there was no internet in 1994 and looking up transverse myelitis and I was totally freaked out because there was so little available to explain what transverse myelitis was, even though that diagnosis had existed for 100 years. There was so little in the medical literature and there was absolutely nothing for a person who had transverse myelitis. We knew that education was going to be a critical component of the work that the association was going to do.

[00:02:52] The doctors who are here this weekend to present about all of the rear neuroimmune disorders, we are so grateful that they donate their time helping to educate the people of our community but we are most grateful for the fact that they are devoting their careers to doing the research on these disorders and offering clinical care, the best clinical care possible to our community and to all of you we are so grateful for your involvement with our community.

[00:03:40] I also want to take a minute to thank our staff for all of the work that they have done to put on this program. This takes so much time and effort to put together from figuring out the agenda to working through all the of the logistics, fortunately I don't have to do this anymore, but I know how much work is involved because I used to be involved in the day-to-day planning of these things. If you're a staff, please raise your hand and be recognized for all of the tremendous work.

[00:04:30] I was talking to our staff this morning through my tears telling them just how unbelievable it is to me after an association that was a totally volunteer effort for 17 years until we hired Chitra for us to have grown into the organization that we have become. I told them they would have to be at my kitchen table with me and Pauline and my mother and father stuffing newsletters into envelopes to really appreciate where we have gone in the history of our organization. It's really been quite miraculous and I'm grateful for the work that you guys do every single day. We are so blessed to have you doing this work and for all of what you give to this organization and most importantly to the people in this community.

[00:05:35] In 1997 Doug Kerr came to the first education program that TMA did in Seattle. He was a senior fellow at Hopkins, and he was trying to figure out what he was going to be when he grew up. After that symposium he was so touched by the people who attended that meeting and really moved by how little was understood about transverse myelitis and I could say about all of these rare neuroimmune disorders that he decided that he was going to specialize in transverse myelitis, and he started the first TM Center of excellence at Johns Hopkins, and he changed the world for all of us.

[00:06:32] He began doing research. The TMA was a very small, very poor organization in those days, but we were able to scrounge together enough money for Doug to hire a research administrator who was a graduate of the Bloomberg School of Public Health and that was Chitra Krishnan. Chitra has been involved in this community for a very long time and two of his fellows, the earliest fellows that he trained in this program for rear neuroimmune disorders were Ben Greenberg and Michael Levy. The impact that he has had on this community has been really tremendous and they continue to make such a profound difference in our community, the research they do, the clinical care that they offer and fortunately for us, they also happen to be just unbelievably wonderful human beings. We have been just truly blessed to have them a part of our community. With that, I'm going to introduce Ben Greenberg.

Ben Greenberg: [00:08:01] Thank you, Sandy. To the staff and the SRNA for the organization and the invitation to be here today. I thought I'd start by clearing a few things up and pointing out a few things. One, Doug has not grown up yet, so if we're talking about what he's going to do when he grows up, we're all still waiting. I also thought it was great, the description of stuffing envelopes. Some people will ask what are envelopes? When the TMA started, there was only mail there wasn't email and things changed dramatically then. When people would get diagnosed, they would literally call Sandy's home phone. There was no online portal to enter your information or send a text.

[00:08:42] When I attended my first, at that time, TMA symposium, my oldest daughter was one year of age, my younger daughter wasn't born yet, and she's now at home working on her college applications. So, it's been an interesting existence. This was all black when I started and somewhere around age 12 for Rebecca, this started going gray. It's great to be here and it's great to see the evolution from the Transverse Myelitis Association to the Siegel Rare Neuroimmune Association.

[00:09:17] It's important to note, the name change wasn't just about honoring, the founders Pauline and Sandy and all the work they did, it was something that the board struggled with for years in recognition that the organization that started off focusing on one rare disease rapidly grew to a community for multiple rare disease individuals and families affected. The mantra of the organization was, there's a lot that we can learn from each other regardless of the letters that come with our diagnosis so this alphabet soup of TM, MOG, NMO, ADEM, AFM on and on and on and on and on and on.

[00:10:04] There is a tendency for all of us to crave and want our own identities as patient groups and as patient organizations and advocacy groups. Sandy and Pauline hung fiercely to the belief that there was something to be gained by a bigger tent community of putting these different individuals together and for those of you in the room who started off with one diagnosis and then flipped, you would have had to go from patient organization to patient organization and the idea here is a recognition that things are fluid.

[00:10:40] The panel discussion we're going to have when we launched in a moment is really going to highlight the unique aspects of what we have all experienced with different diagnoses and the commonalities that we've all experienced with these different diagnoses. I too want to thank the organizing groups, not mass general, but everybody else the sponsors who were listed are our partners in corporate America as well as Kennedy Krieger Institute, which helps support today. We are very grateful for creating an environment where we can all come together, and it's very much appreciated.