Meet Our Non-Profit Partners

Moderated Panel Session

You can view this presentation at: youtu.be/WTJgJaLmzl4

[00:00:00] **Roberta Pesce:** Welcome back, everyone. Our next session is a conversation with our advocacy partners. Thank you all for being here. Joining us are Sandy Siegel, president of the Siegel Rare Neuroimmune Association, also known as SRNA. Jacinta Behne, the executive director at the Guthy-Jackson Charitable Foundation. Welcome. Sumaira Ahmed, founder of the Sumaira Foundation. Cody Unser First Step Foundation. Judy Lefelar, the executive director at the MOG project. Katie Bustamante, director at the Acute Flaccid Myelitis Association, AFMA. And Chelsey Judge, the scientific advisor at the Connor B. Judge Foundation. This panel will be moderated by Chitra Krishnan, the executive director at the Siegel Rare Neuroimmune Association. Chitra, over to you.

[00:01:00] **Chitra Krishnan:** Great. Thank you so much, Roberta. A heartfelt gratitude to each and every one of you for taking the time to join us for this conversation. As I look at this mosaic, as you called it, Jacinta, a few minutes ago, it is such a pleasure to see friends I've known for about 20 years and friends I've made over the last few years. So, it's really exciting that we're all here having this conversation. I know we all have shared passions, shared interests, shared missions, and maybe our story should start with sort of how our foundation started. So Sandy, I'd like to start with you to talk briefly about then, TMA, now, SRNA.

[00:01:44] **Sandy Siegel:** Thank you, Chitra. So, in July of 1994 Pauline was diagnosed with transverse myelitis. She was a kindergarten teacher in a public school in central Ohio, and Pauline was totally paralyzed from the waist down. And we found out very quickly that physicians did not understand transverse myelitis, and we started looking at the medical literature and were shocked at how little research was available. There was a 1983 Israeli study on incidence, and there was a case series study, that was about it.

[00:02:37] That was frightening, that there just wasn't any research out there. There was no Internet, and so there was no way for us to connect with other people, there was no organization, no doctors specializing in transverse myelitis, and so we felt like we were off on an island, and it was a horrible, isolating experience, and it's a long story, and I'm not going to get into it, but we found a family from Tacoma, Washington, who Cody knows, the Gilmer family, who had an 18-month-old daughter who was diagnosed with transverse myelitis, and working with the Gilmers we started the transverse myelitis association. We were under 200 people at that time, and almost all from the United States. Now we're more than 14,000 people from more than 110

countries around the world. We offer education, support, we support research on all of these disorders, and we train physicians and researchers, so we're involved in all aspects of all of the rare neuroimmune disorders.

[00:04:08] **Chitra Krishnan:** Thank you, Sandy. Cody, you and your mother, Shelly, started the Cody Unser First Step Foundation.

[00:04:17] **Cody Unser:** Yeah, so it's so great to be here with all of you. So yeah, so in 1999 I was 12 years old, active child, I grew up in an auto racing family, so we were always on the go, and on February 5th, 1999, my life completely changed when I was at after school basketball practice and my left leg went completely numb. My right leg was kind of a tingling, and I couldn't breathe, I had a hard time breathing, I got the worst headache I've ever felt.

[00:04:52] And so the school I was attending at the time called 911, and I went to the hospital, where kind of similar to everyone's stories, the doctors had no ideas what was going on. I couldn't walk, couldn't urinate. They also thought I was making it up because my parents were going through a divorce at the time, and they sent me home and just said drinks lots of fluids. I woke up and my belly was extended because I couldn't urinate, but they wanted me to drink lots of fluids, so it was very scary. Had no idea what was going on. Went back to the hospital. With a round of tests they came back with my fate of transverse myelitis. Had no idea what that was, what it meant. I just knew that my life had completely changed because I was 12 years old and now paralyzed.

[00:05:46] So long story short after rehab and just dealing with anger and sadness and frustration, I knew this happened to me for a reason, and I wanted to do something about it, so my mom and I created the Cody Unser First Step Foundation. And I was, back then in 1999 I was probably the fourth case seen here in New Mexico, so we knew that it was a rare disorder, but also one that's completely misunderstood, often misdiagnosed.

[00:06:16] So we got on that sort of train that Sandy was talking about of bringing awareness to transverse myelitis, getting doctors and researchers to talk, share data. This shouldn't be happening, we should be diagnosing, we should be studying this, so the Cody Unser First Step Foundation was started with the full principle of awareness of transverse myelitis and it's kind of evolved over the 22 years into we do a lot of advocacy work with other organizations, and we have a quality-of-life program, so I'm a big scuba diver. So, I try to help people with disabilities get into the ocean and get certified, to know what's possible in life. So yeah, that's me and my foundation in a nutshell.

[00:07:02] **Chitra Krishnan:** Thank you, Cody. Jacinta, I'll turn to you. I think it was a similar conference. Probably it was not called rare neuroimmune disorder symposium back then, or maybe it was, it was 2008, and I think I met you and your colleagues, and that was when the foundation started, am I right?

[00:07:21] **Jacinta Behne:** That's exactly right, we were 10 minutes old, Chitra. And I'll never forget, because it was all men around the table, you walked in the door. I was so happy, and so wonderful. Thank you, Sandy, thanks to your whole team. You're such a delight to work with and thank you for this opportunity today. Guthy-Jackson Charitable Foundation started when, well, Ellie Guthy had her first attack in 2008, early 2008. The formal start was August 1st, 2008, and at that time listening to you, Sandy, I thought we had a tough time, because I could go to the Internet. There was hardly anything there, but when I heard you say there was no Internet, it really struck me, Sandy. I can't imagine how you went about what you did. Tremendous effort, and Pauline was a beautiful lady, and I know you worked closely together, and it certainly has paid off until today.

[00:08:25] Anyway, back to I found there were three things on the Internet. The NIH had a one-page white paper. The was a Wikipedia page on Eugene Devic, who described a monophasic condition which later

became Devic's Disease, precursor to NMO. And then the third one was a research paper published by the Mayo Clinic, and Vanda Lennon and Brian Weinshenker describing this aquaporin-4 IVG water channel, which soon became our biomarker, which for us has been everything, because unfortunately there are a number of autoimmune diseases that don't have that, and it's been a great help to us.

[00:09:08] Everything we do we try to extend beyond NMO to all autoimmune diseases. Trying to, a rising tide raises all ships. And that's really our goal. Just real quickly I feel like I need to talk really fast, so stop me if I talk too fast. We knew immediately August 1 we began, November 8th we brought researchers together for our first, what we called round table conference. We knew we needed to get neurologists together to start a conversation. Those conferences have happened annually since then. Lately virtually, but still, thank you, Zoom.

[00:09:46] Then after that we knew we needed to bring patients together, that was a year later in 2009. That's happened additionally every year, lately virtually. We are planning our next international NMO roundtable for patients in this coming March, pandemic allowing. We're going to be optimistic. So, we needed to get people together to talk, first of all.

[00:10:09] We knew we needed to come up with diagnostic criteria, because when I first started, NMO was a variant of MS. Well, we know that it's very well differentiated, just like MOG today. You're becoming very well differentiated, and that's necessary. And diagnostic criteria are necessary. So, we pulled a committee together globally, 20 wonderful neurologists spent 2 years, researched lit review of 250 papers.

[00:10:36] The result is we knew it was a spectrum disorder, and that's why we have, every neurologist hopefully has access to these criteria for an accurate diagnosis. We also knew that we needed to invite industry to come together, meet, and look at repurposing drugs that were sitting on their shelf that failed their clinical trials, to see whether there might be use for them in NMO, and we know the result of that was very positive. That was a tremendous year for us in 2020. I'm going to talk faster.

[00:11:10] We knew we needed to build an international clinical consortium, so we had reached out to neurologists worldwide from the US to Australia, we need to collaborate internationally. It's not just the US that needs to talk together, we knew that, so we now have an international consortium of about 110 neurologists, 30 countries who come together, research together and publish together.

[00:11:32] We also knew that we needed to start a data and biospecimen gathering study, which we called CIRCLES, because there needed to be resources to do the research on. Now we're engaged in what's called SPHERES. CIRCLES collection phase came to a close. SPHERES is a regulatory grade study because let's face it, yes, it's great to have therapeutics, but those were short term studies. Now we need to know patient safety and efficacy. I'm going to stop there because it could go on too long. I hope I didn't go over my 2 minutes. Thank you for everything, thanks for letting me join.

[00:12:07] **Chitra Krishnan:** Thanks, Jacinta, and I know you'll be talking about the CIRCLES study tomorrow, so people will get to hear about it as well. Sumaira, I think it was 2018. I actually went through my e-mails; it was the first e-mail exchange I had with Sumaira. It was your story you shared on our blog; it was 2018. I went back and read it again and our correspondence, and it brought me back memories, but thank you for being here. So, I'd love to hear your story and how the foundation started.

[00:12:37] **Sumaira Ahmed:** Well, thank you so much for having me, and what an honor to be in this panel alongside so many inspiring patients, caregivers and advocates who have really risen to the occasion to do what we need to do for all of our causes. So, my name is Sumaira, I am an NMO patient myself. Also, the founder and executive director of the Sumaira Foundation.

[00:13:02] I got diagnosed with NMO 7 years ago, just a few weeks after my 25th birthday. Obviously, my whole life changed, and I felt that there were some gaps in our community that needed to be addressed, and I basically looked at my skill set, what were things that needed to be, what were voids that needed to be filled, and sort of decided to start a foundation to hopefully address that.

[00:13:35] So in short, over the last 7 years we have been dedicated to raising awareness of the disease or diseases now, as the founding philosophy was that heightened awareness would ultimately lead to more research and funding for research, and maybe get us as close to a cure as possible. We fundraise to support research, so we have a number of research grants, and are very passionate about building a community of support for patients and their caregivers, because as a patient having gone through this myself, I don't think anybody should go through this alone, so I'm very passionate about that, and we've just added a fourth pillar to our organization which is advocacy, and I/we are going to do everything in our power to elevate the patient's voice to help inform decision making that directly impacts patients and their caregivers, and hopefully it works out, but thank you so much for having me.

[00:14:43] **Chitra Krishnan:** Thank you, Sumaira. Chelsea, I'll turn to you. I think several years ago I remember getting an e-mail from your mom when Connor was diagnosed with NMO.

[00:14:56] **Chelsey Judge PhD:** Yes.

[00:14:57] **Chitra Krishnan:** Yeah, please go ahead.

[00:14:57] **Chelsey Judge PhD:** Thank you. So, you're going to hear a lot of repeated themes that other panelists have already shared. It's almost eerie, but then in some ways I guess that's empowering. Very similar to Sumaira, my brother, 7 years ago was diagnosed with NMOSD, he was 22 at the time. Obviously rocked my family's world, so the Connor B. Judge foundation was started in honor of my brother, Connor.

[00:15:27] My mom and I established the foundation after Connor's first profound NMO attack of blindness and paralysis. To say that we're grateful for all of the work by many of you other patient advocates, patience, bravery in clinical trials and research, researchers, clinicians who made so much progress, so that when my brother was diagnosed in 2014, he could actually receive necessary help, that that available science and medicine and all those tools were there, just wow. And we saw that, we were very aware of that, but that's why we're all here, we all know that there is still much more work to be done.

[00:16:12] Ironically, as my brother's diagnosis was happening, I was working on my PhD in immunology, and I was terrified by what I thought, I was asking just basic immunology questions and they couldn't be answered. And this isn't a knock on clinicians, some of them just, I realize now, we do not know the answers. My brother's diagnosis, treatment and prognosis was dependent on our family's support and resources, including my scientific background and the amazing, compassionate clinicians who effectively kept up and communicated to us and with their patients the emerging science. That's super important and we all know that.

[00:16:53] We realized that while what happened to Connor was tragic and awful, that his timely diagnosis, his swift acute treatment, that gave him his ability to recover, to see, to walk again, and obviously still lives with neurological deficit, and that is a part of the gap that we're trying to fulfill. But he also got appropriate long term, again, compassionate clinical care and preventative treatment. But that's still unfortunately lucky, and that's what we're trying to help eradicate. That it's just standard, that you don't need to be lucky to get proper diagnosis and treatment.

[00:17:30] So our mission at the CBJ foundation is to promote awareness and research funds for NMO in a collaborative way, as we're all here. Our major focus has been nerve repair research so far. Of course, understanding COVID and NMO, and just patient focused education and connecting patients, researchers, and clinicians. Just very grateful to be here, and very grateful for this amazing community. Thank you.

[00:17:57] **Chitra Krishnan:** Thank you, Chelsey. Katie, I'll turn to you. I so clearly remember photographs of your beautiful boy, Alex, when you shared your story with us. And so, I'll turn it to you, so if you'd be willing to share more.

[00:18:13] **Katie Bustamante:** Yeah, of course. Thank you for having me, I feel privileged to be with all these people who have gone through so much, and I think the pervasive theme here is no one knows what's going on. There is no diagnosis, or if there is, there's very little information available. So, we have that experience as well. My son was affected by AFM on December 24th in 2016. He said he couldn't move his thumb. I took him to the emergency room, and by that evening he could barely walk, and he basically just melted before our eyes, and ultimately was paralyzed from the waist up including his diaphragm, so he was on a respirator. It took 4 or 5 days for them to even come up with a possible diagnosis, and it was either going to be transverse myelitis or acute flaccid myelitis. Unfortunately, he had AFM.

[00:19:26] We were in inpatient therapy for about 6 months and then they sent us home because basically it was like there's nothing more we could do, and then we lost him in spring of 2018, from respiratory complications, and he was 6 years old when he passed away. So, in December when we looked it up there was nothing available unless it was very, all the language was very clinical, but there no resources available.

[00:20:03] Our saving grace was a Facebook group of parents who had experienced this, because it most often affects children. So, in December we were invited to go with them, they were planning a group trip to go to DC and to meet with the CDC, and it was about six months after Alex had died, so of course we went, and we met with the director there and kind of got the ball rolling on why haven't you guys done anything, and you knew about this years ago and you've just done nothing. So, meeting all those parents was great, and then we all seemed to have such similar stories, where there's nothing available.

[00:20:50] You get this diagnosis, you try to research it and there's nothing to do, so we were really bouncing off one another what works, what doesn't. So, my husband has been working in nonprofits most of his career, so we got together with a few other parents and created our association in order to be a resource for families so that they have somewhere to go to, and some kind of guidance.

[00:21:18] So we provide information and just kind of guidance, we get a lot of, we try to help those with a new diagnosis, and here are facilities available, and here's the information we know, and here's a parent group so you can vent, and here are similar stories, so support is there and you're not feeling like you're on the island, because I think a lot of us felt that way, you're all alone. And then we're also providing grants, because there's so little information about it that insurance won't cover things because there's no proof that it works. So, we provide grants to a lot of families who need therapy or equipment or other specific items that insurance won't cover. So, we don't work on the research side, we're more a support system for families and we want to help families know that they're not alone and give them what they need. So that's basically what we do.

[00:22:31] **Chitra Krishnan:** Thank you, Katie. Julie, I'll turn to you. I don't think it was that long ago I was sitting with you and your daughter at Starbucks near us and were having a conversation, and the MOG project has grown. It's so nice to see you.

[00:22:47] **Julia Lefelar:** It is nice to see you, and I'm touched and honored to be part of this group, and I'm so, just it's a heartfelt sentiment that you all have, based on a lot of pain and suffering, that I totally understand. My journey with MOG started probably 20 years ago. I had horrible chronic fatigue; I was ill basically until I blew up into optic neuritis in 2014.

[00:23:21] I had a lot of disability from the fatigue that I went through at the time, I was shifted around the medical system with no diagnosis, and I was actually lucky to have the optic neuritis happen to me. It sort of validated that I truly was ill with something. I was really lucky to having gotten into the hands of Dr. Michael Levy, because I'm lucky enough to live near Johns Hopkins. He helped me. I had NMOSD at the time, the MOG antibody test was not really available widely, and so I was actually not diagnosed with MOG until 2017, late 2017, when I kept relapsing from medicine that really wasn't working for me.

[00:24:14] When I found out that I had MOG I was actually happy, because something, after probably 17 years, something had come to me that actually made sense on why I had been feeling ill for years. And so, my daughter and I were looking, and my husband, my whole family actually, but specifically my daughter and I were looking for information, and like everyone else there was just nothing out there, or it was old, it was wrong. MOG is a new frontier, it's a new disease, and so we decided to start maybe advocating for this, for better information.

[00:24:55] Dr. Levy led us to the TMA at the time, of course this is the SRNA now, and we met Chitra, and we met Sandy and all the others that work there, and we were just amazed at how kind they were. They took us under their wing, and they said yeah, please help us launch our MOG advocacy. We brought in some other members, and they had also gone through some really horrific diagnosis stories, or I should say misdiagnosis, or nondiagnosis stories as well. One of our members is completely blind from the disease.

[00:25:39] MOG can be relapsing, it's tough to get under control at times. For some people it's easy, and I'm one of the lucky ones, I had a good doctor and the medicines worked for me, so I have little disability now, I have very, very little disability, but the future's always unclear. So, we worked with the SRNA to help them develop the wonderful resources that they have on their website. They did a fantastic job of making that available for everyone, and then in 2018 we decided that we wanted to put real focus on the disorder, and yet we wanted to stay connected with the SRNA, because Chitra, we talked about it and it's stronger together.

[00:26:28] We really need to continue our advocacy and our work together, and we formed the 501[c][3] organization, and honestly, we thought it was just going to be a couple of car washes and maybe a bake sale, but it turned into this now global patient led network, and we're just continuing to push for growth, because, five years ago there was nothing for MOG and they've come so far in their knowledge of the disease. They have started to develop treatments, we don't have any FDA approved treatments, and the MOG project has been pressing and putting proposals with the CDC and the World Health Organization to make it its own disorder, and so we've been working closely with them.

[00:27:20] We hope to have an insurance code for those with MOG within a year or two, so we'll just continue down that path, advocate, try to push for research. I'm hoping that clinical trials are coming. I understand that they will be. We are going to continue to grow that patient led network, and we are thankful for our partners at the SRNA and the Sumaira Foundation for NMO, because I don't think we would be here without the help of others. Thanks for having us here.

[00:27:55] **Chitra Krishnan:** Thank you, Julie. I have to say, I'm so humbled by listening to all of you, and I can sort of see so many partnerships and collaborations that have started and they continue to, like one that comes to mind is the ABCs of NMOSD pod cast that Jacinta, Chelsey, Sumaira were all involved in, and

I think were it not for us doing it together, we would not have the sort of reach. Not only just the community, but even the medical professionals, and so I am truly humbled, and what a fantastic collaboration thanks to a research grant we got from Horizon Therapeutics. So I'd love to sort of open it up for a few of you if you'd like to share about partnerships that you've all been engaged in amongst each other. I know, Julie, you just talked about the work you do with us and with the Sumaira Foundation. Jacinta, do you want to take a few minutes to talk about some partnerships that you have? I think you may be on mute, Jacinta.

[00:28:56] **Jacinta Behne:** You know, sometimes it's better if I stay muted because I talk too much or too fast. Yeah, thank you very much. With that, collaboration is just those of you here on the screen, and some that I hope we can work more closely with. Everybody wins, there are no losers, and we've had, because of the kind of work we do, we do work with academic institutions for research, domestic and internationally, and that's a really important thing, but collaborations really extend to even who would ever guess that Google, of all places, has a life sciences division called Verily that does tremendous work in computations analyses and such, which helps us arrive at knowledge about biomarkers.

[00:29:47] So it's taken us some places I didn't ever suggest or guess would happen. University of Utah data coordinating because you need the data some place to go to that's going to work with you on data. So, it's very an industry, they're actually very highly collaborative, and when I say that people look at us like are you kidding, but they are. So, all I can say is it's a broad spectrum, we're very fortunate and very happy to continue going. My great goal for the future is that we can all continue. We've started to work together for global patient advocacy. We've learned that internationally there aren't a lot of formalized patient advocacy groups, so we're working really hard to grow that patient advocacy, and you'll be hearing from me, you all, for our next step in that direction. Thank you.

[00:30:43] **Chitra Krishnan:** Thanks, Jacinta. Katie, what do you think is your hope for the future for our community?

[00:30:54] **Katie Bustamante:** I mean, obviously ideally, we wouldn't need ourselves but that's not going to happen. For the future obviously we'd like to grow and be able to provide more research or more grants for people so that we're not as limited. We just started doing kind of an ambassador program, so when a patient is newly diagnosed, we find someone in their area so they can have a single point of contact, because you have so many questions, and I've played that role, and I'm happy to say the child that was affected and paralyzed for about a month, he made a full recovery.

[00:31:39] But in the meantime, when they were in the hospital, I was able to be that person for her, and so we're trying to expand that program to where you do have someone where you can kind of vent to and get information from and get some guidance and know that you're not alone. So that's definitely on our docket for upcoming years, and then we'd like to be more aggressive about applying for grants so that we can provide more for our community.

[00:32:11] **Chitra Krishnan:** Thank you, Katie. Cody, your vision for tomorrow?

[00:32:16] **Cody Unser:** My vision for tomorrow. Well, kind of just echoing was everybody was saying, I think we are a very special and unique community, there's a lot of research towards cancer and other disorders that are sort of larger on a scale, but I think all of these disorders really do affect people's lives, and we definitely have stories to tell. It's not, they don't get told enough, but I definitely think the community is strong.

[00:32:50] My mom, when I became paralyzed, I think she went to the first or second symposium in, was it Columbus, I think, and met Sandy. And it goes to show the strength of organizations and the fact that we

can provide resources, also research. So, I definitely want to continue talking with all of you and working towards kind of the caring for other people, and then also researching for a potential cure one day, but there's strength in numbers. Again, it's an honor, and just trying to push for more research and help and support.

[00:33:40] **Chitra Krishnan:** Sumaira, your vision for our future?

[00:33:42] **Sumaira Ahmed:** Well, as the saying goes, it takes a village. So very happy to have such supportive partners in this space because we definitely can't do this work alone. It's a very big lift. My vision for the future, kind of since the beginning I've said that for as long as I have energy and time on this planet, I will work towards helping this community find a cure and living the best possible lives that they can live beyond their diagnosis. So, I think just in the last 7 years of living with this and seeing how many strides we've made as a community, I remain hopeful and optimistic for our future. I really do believe that our futures are very bright, and I'm looking forward to seeing what we all do together and individually.

[00:34:42] **Chitra Krishnan:** Thank you, Sumaira. Chelsey?

[00:34:47] **Chelsey Judge PhD:** I always get emotional. So, I think the future is this, I think that it's continuing to work with this close-knit education focused, warrior attitude rare neuroimmune community. All of these organizations have been pivotal to any successes that we, just at our foundation have had, like the ABCs of NMO, working with the Sumaira Foundation for demystifying NMO. That has been huge, and also crazy to host a pod cast. Clinicians, researchers, bringing together rare disease day in Cleveland with the National Organization for Rare Disorders. Creating the first ever NMO patient day with the Cleveland Clinic, and getting the help from industry, Guthy-Jackson, and others, and I think that the future is just more of these, like very collaborative, compassionate strategic partnerships to promote relevant science and information for patients and their families, support, resources. NMO is such a devastating disease, but there is so much hope, and I think that the future is incredibly bright because of everybody in this community.

[00:36:04] **Chitra Krishnan:** Thank you, Chelsey. So beautifully said. Julie?

[00:36:10] **Julia Lefelar:** Yes, thank you, Chitra. Listening to everyone, I think that your hopes for the future are just not very much different than ours. As we sit down and look at our road map for the future, we have a strategic plan sometimes that changes, but we cannot see that being any different than how it's been in the past with working with the partners that we work with. We wouldn't be here without this collaboration. Our goals are simply to, at first to get NMOSD and MOG sort of sorted out. We have a MOG antibody, and we do believe it is, and we're along with other researchers, believe that it should be its own disorder, and targeted therapies need to be created for MOG. But what that means for everyone else as they explore MOG and the MOG antibody, is that understanding will open up about the immune system and how that's affecting other demyelinating conditions.

[00:37:25] We're lucky that we have an antibody, and I hope that they discover mechanisms in the immune system as research goes on that sort of opens up understanding about what's happening in other disorders like transverse myelitis and AFM, and we have hope for the future, and we're going to continue working together. That's the most important thing. We have projects that we're constantly thinking of, and ways to help the community, but affecting research has to be our number one objective, because we have to have something that works a little bit better than what we have now for MOG. You know, it is a patient led organization working together with pharmaceutical companies, researchers. We have a wonderful medical board that are so generously devoting their time to us. I think we're very lucky and the future's pretty hopeful. So, thank you.

[00:38:30] **Chitra Krishnan:** Thank you. And closing thoughts, vision for your future, our future, our collective tomorrow. Sandy?

[00:38:40] **Sandy Siegel:** Well, I'm going to start by saying acute disseminated encephalomyelitis, because it hasn't been mentioned, who just I needed to say that. We were the Transverse Myelitis Association for a very long time only because I didn't have the time and energy to do something about changing the name, that's just the reality. Because I've done this work from the beginning as a volunteer, raised a family, worked a full-time job, this was an evening and weekend proposition for me.

[00:39:23] So changing the name was just not on my radar screen, but it wasn't because we didn't have a reason to change the name, because we learned about NMO and ADEM very early on. AFM and MOG are, they're new diagnosis, but they're not new disorders, people have been getting these disorders for as long as ADEM and transverse myelitis were diagnosed, but we learned about them very early, and we were all in agreement including the physicians in our community that we were going to open an umbrella, and that everybody was going to fit under that umbrella, and it's way bigger than what even we're talking about.

[00:40:12] There are people with vascular myelopathy, radiation myelopathy. There are so many disorders that affect the central nervous system, and we basically take all comers, because they have nowhere else to go, and that's frankly how NMO became a part of our community, and how ADEM and all of these disorders became a part of our community. My perspective is and has always been that there is so much more that we don't know than what we do know, and the distance between the knowing is getting the research done and getting clinicians and researchers to specialize in these disciplines. So we started the Jim Lubin fellowship to train clinicians and researchers, because too many people in our community are being treated by a general neurologist who doesn't understand the lay of the land, and so being able to grow that discipline is absolutely critical, and that is what we're doing with our fellowship program, and it is also creating researchers, and there is, to me, all of these diagnosis are in Jell-O, not in concrete.

[00:41:36] The boundaries around them are a moving target and that's why looking at all of these disorders together is so important, and I think that is going to be our focus going into the future, and I think our hope for the future and our hope for the quality of life for the people in our community is going to come from being able to grow that research. When Pauline died in 2017, I had to ask myself why are you going to continue to do this work? And the answer to that was this work has become so much bigger than Pauline and me. It's about all of you, it's about the communities that you represent, and I think a part of Pauline's legacy is watching people's lives improve who went through the same kind of experience that she went through. That's the hope for the future.

[00:42:53] **Chitra Krishnan:** Thank you, Sandy. Thank you all so much, I am so hopeful for our collective tomorrow. I heard the words brighter future several times in our conversation, and I hold that thought very dear, so thank you all. I appreciate you being here.

[00:43:13] **Julia Lefelar:** Thank you, Chitra.

[00:43:14] **Cody Unser:** Thank you.

[00:43:15] **Roberta Pesce:** Thank you. Thank you again, all, and this was definitely a heartfelt conversation. So, thank you all very much for being here, and to all of the participants, we will be back very soon with our next talk with Dr. Kabo on UTIs, catheters and incontinence. So, see you all soon. Bye, everyone.

[00:43:38] **Jacinta Behne:** Bye, thank you.

[00:43:39] **Sumaira Ahmed:** Thank you.