Welcome

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[00:00:05] **Dr. Sandy Siegel:** Thank you all for being here. I feel like I'm at a reunion. Pauline had an inflammatory attack in July of 1994, and then this happened. And, if I described this, that's what we would be doing for three days. So, I'm not going to get into all of this. It became an organization, and most importantly, a community of 15,000 people plus from more than 120 countries around the world.

[00:01:12] Pauline was a kindergarten teacher. I was a cultural anthropologist, and neither one of us had the training or experience to do any of what we set out to do and ended up accomplishing. After doing the work for about 20 years, I decided, after realizing that I'm probably not going to live forever, that I had an obligation to share what I had learned over those 20 years because I had learned a lot.

[00:01:54] When people called the Transverse Myelitis Association, which is how we were known in those days, my telephone rang in the kitchen, and I am sure Pauline and I spoke to hundreds and hundreds, maybe thousands, of people over the years. We knew absolutely nothing about these disorders when we started the organization, and I administered a survey just to collect information.

[00:02:30] When I sent out the first newsletter in 1997, and we had 815 respondents to that survey that I spent years analyzing, and Jessie Danninger and I presented the results at the symposium in Baltimore in 2004. I had attended every single education session at all of our symposia for years. I read every article that was published in the medical literature, and I seriously picked the brains of every medical expert in our community. And I had lived with Pauline for 25 years and lived through the experiences that she had with transverse myelitis.

[00:03:22] The book is called *The Patient Experience with Transverse Myelitis: An Anthropological Perspective*. I did it about TM because that's what I understood best, but really, that book is about all of these disorders. And if you haven't figured it out yet, doesn't matter what is causing the symptoms that you have; you're all going to get treated the same way.

[00:03:49] So, much of the book applies to all of the rare neuroimmune disorders, and it's an anthropological perspective because I am describing what I observed. I didn't and never gave medical advice, so the book does not include any kind of medical advice. It covers many, many different subjects, and people from our community who are here this weekend, and also medical professionals who are going to be presenting this weekend, wrote articles for the book as well.

[00:04:34] I wanted the last words of the book to be Pauline's because none of this would have happened without her. She had retired as I was getting the book completed. She had been an elementary school teacher for 25 years, and she was exhausted. So, I didn't want to hound her about, "I need your conclusion, I need your conclusion." I just left her alone. Finally, in 2017, before we were to go on a vacation in Montana for three weeks, she handed me her conclusion, and she passed away on that vacation. And I have asked Ben to please read that conclusion for me.

[00:05:44] **Dr. Benjamin Greenberg:** So, it's an honor to be speaking Pauline's words. I'm gonna begin with the title, and I want everyone just to think about it for a moment: *Blueprints, There Just Isn't One*. "It has been 23 years since my old life ended and my new life began after my transverse myelitis attack. There are many thoughts and feelings that have stayed with me through this experience and that I believe to be true.

[00:06:13] One, I believe I was meant to get TM, so that Sandy could help me and all who suffer from these rare neuroimmune diseases. Sandy has the intelligence, confidence, and extraordinary character, and passion that made it possible to make and build the TMA and make it the family it is today. One would need only meet Sandy to see he is a genuine and quality person. His inspiration touches your heart and makes you want to be a better person.

[00:06:43] Sandy believes in people and knows the greatness in each person. Everybody needs someone to believe in them. Everybody needs a Sandy. I am blessed to have mine. Second, you must be brave for yourself and other people. It is all about hope. We are suddenly in a world we know nothing about. I was fortunate to be moved to one of the top 10 spinal cord rehab hospitals in the US.

[00:07:09] I was met by an entire team of people, all there for my well-being. After the team introduced themselves, I told them, 'Great. I'm a kindergarten teacher. I'm a butterfly. I dance around the room. So, this is not going to work. You do what you need to do, and I'll do what I need to do, and everything is gonna be okay.' This memory is one of many I will never forget.

[00:07:38] Third, the little things in life are really the big things in life. Fourth, it is important to find humor wherever you can. When in the hospital, I started each day by using a mirror to look at my butt. This was very serious because I was checking for pressure sores, which are life threatening. After 25 years of being an elementary teacher, I retired this year; my body was just not able to manage all the responsibilities and stress. I haven't felt this good since I started teaching."

[00:08:17] So, I have to thank Sandy for sharing and Pauline for sharing her words, and it's really ironic that the words of a petite, beautiful, quiet woman are being spoken by a very large, loud man. So, this is somewhat odd. You may have picked the wrong person. I don't think you got the full effect of Pauline. But, as a way of welcoming everyone to Dallas, we thought there was no better way than to start with the founder of the organization we know and love, Sandy, and the words of Pauline, who made this all happen. So, thank you, Sandy, for sharing.

[00:09:00] So, you know an organization has aged if the founder talks about answering the phone in his kitchen. That's a very old-fashioned phrase. But part of the beginning, if not the very foundation, of the organization was about community, was about bringing people together. Because in the world of rare disorders, it is very powerful to meet other people who have been through the same thing as you have. And it is not just powerful for patients or for families, but in this room are mixed patients, caregivers, clinicians, and scientists.

[00:09:38] And it's extremely powerful, speaking now as a clinician, as a scientist, to be part of this community, because we learn so much more from you than, frankly, you learn from us. But we're trying to get better at it. I've been thankful to be part of symposiums now for -- where's Chitra? Is it 20 years now since my first symposium in Baltimore? Yeah, so it's 20 years. Damn, you're old, Doc.

[00:10:09] So, it's been a long time, and I have to say there are a couple of things that haven't changed at all, and some very important things that have changed significantly. So, first, just the incredible sense of wonder bringing community together, and the new relationships that are built, and the new friendships that are made, and the new collaborations that are built hasn't changed in 20 years. What has changed?
[00:10:34] So, if you just look at the agenda -- and we're gonna talk through it a little bit -- there's a lot more to discuss than there was 20 years ago. There's a lot more meat on the bones, and that's a wonderful thing. Twenty years ago, we were not live streaming virtually. We are today. So, to those of you who are joining us online, we welcome you, and we thank you for your participation and look forward to engaging you and including you in all the ways we can.

[00:10:57] What's also changed is the broader community that's gotten involved. I do want to start off by thanking sponsors for this symposium. We are very grateful to partner with industry and with academic centers including Alexion, AstraZeneca Rare Diseases, Amgen Rare Diseases, Genentech, UCB Pharma, the Kennedy Krieger Institute International Center for Spinal Cord Injury. We thank you all for being sponsors of the program. Before we get into the agenda and the first introductions, I wanna make you aware of a few things.

[00:11:29] So, there's refreshments in the back. There are bathrooms right outside the door. There is a wellness room located in Dock Carchers; it's right down the hall for relaxation, rejuvenation, if you need a break. This is sponsored by UCB Pharmaceuticals; we appreciate it. And so, it's a long day, it's a long weekend, so if you need to get up, stretch, take a break, there's a very nice wonderful ambiance room for you to relax in.

[00:11:53] The KKI Spinal Cord Injury Clinic sponsored the Barista coffee break; we appreciate that. Then there'll be exhibit space in the Stinson room where you can learn from sponsors and exhibitors. We are partnered with the CAN Do MS organization to offer the Take Charge program on Saturday evening and Sunday morning, and we'll give you more information about this.

[00:12:15] So, we are gonna do our best to keep everything on time. There are gonna be sessions where it's open for questions, and we encourage everybody to take part. We wanna hear from all of you and learn from your experiences. If, at certain times, we have to end it prematurely, don't take it personally. There are plenty of breaks and networking opportunities to have discussions and get your questions answered.

[00:12:40] If you look at the agenda for today, we are so far on time, but Carlos is keeping odds. We should be late by the time we get to the coffee break. We're gonna be starting this morning with, probably, what I would call one of the most important sessions for today, and that's the ‘What's My Diagnosis?’ where we invite members of our community to come and share their personal stories about their diagnostic journey.

[00:13:08] This is gonna be moderated by GG, who's coming to the stage now and will invite our panel speakers in a moment. From there, we're gonna go to what sounds like a quiz show called What's My Diagnosis? -- a physician and panel discussion. The point of that is to really bring everyone up to speed on the state-of-the-art for diagnostic criteria. Because if I ask, by a show of hands, how many people in the room who've been diagnosed with rare disorder had the title of their diagnosis changed at some point, from first diagnosis to second, my guess is I get about 80% at least of the hands going up.

[00:13:45] What's really fun is when a group of doctors get together and decide, “Just kidding, we're gonna change it again.” And so, we're gonna play a little bit of a quiz show of What's My Diagnosis? and try and get everyone up to speed on the state-of-the-art relative to criteria and how we go about testing and putting people into whatever category we think of that week.

[00:14:05] So, as you go through the weekend, everyone gets comfortable at their tables, but as we go to breaks and come back, I encourage everyone to mix and mingle. Get to know other people here. The clinicians and other folks who are gonna be speaking welcome you to tackle them in the hallways, ask them questions, get to know them. They really wanna get to know all of you as well.