

Welcome

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[00:00:05] **Sandy Siegel:** It's a great opportunity for all of you to learn and I appreciate all the faculty who are here, who are going to be doing the teaching today. Pauline was diagnosed with transverse myelitis in 1994. She was a completely healthy 35-year-old kindergarten teacher and what seemed to us to be almost immediately, she became paralyzed from the waist down. Her diagnosis began her journey and my journey with this experience. That we would share this journey with 15,000 people was not our plan. There was no plan.

[00:00:54] Pauline and I knew we had to do something and that was the plan. There was no information for patients and families. There was little information for clinicians. There were no specialists. There was no support network. There was no research. None of this work would have happened without Pauline. There would have been no Transverse Myelitis Association without Pauline. We helped to establish the organization with Deanne and Dick Gilmer. There are others who have been involved in this work from almost the beginning, Jim Lubin, Debbie and Michael Capen, Paula and Mike Lazzeri, Steven Miller and many other volunteers from around the world. In 2024 we will be recognizing 30 years of doing this important work. There is too much suffering and sadness surrounding these disorders to refer to our anniversary as a celebration.

[00:01:59] I want to read the following passage from a blog I wrote shortly after Pauline passed away in 2017. In Judaism, there isn't an emphasis on the afterlife, not at all like Christianity. I can't remember any sermons by my rabbis about a connection between how I behave or what I do with my life and an eternal reward. Afterlife was and remains a vague concept. What is emphasized in Judaism is being remembered. The anniversary of a person's death is their Yahrzeit. There are prayers said and loved ones light a candle that burns for 24 hours. There are four times during the year that a Yizkor services service is held to remember loved ones who have died. Yizkor services literally means remembrance. These are solemn and holy, and loving remembrances.

[00:03:06] In Judaism, we never name a child for someone who is alive. We name them to honor and to remember a relative who has died. We are about remembering. I recognize Pauline's Yahrzeit and I go to Yizkor services for my Lebanese Catholic wife. I know Pauline would love being remembered in this way by me and her family and friends. Today is one of those Yizkor services. I said the Mourner's Kaddish for Pauline and for my father this morning. It is important for me that Pauline is remembered by her family and friends, and it is also important for me that Pauline is remembered in this community. I want to end by reading one

of the meditations that we often read before saying the Mourner's Kaddish, the mourner's prayer or maybe I should have somebody else read it or you'll just have to watch me cry my way through this.

[00:04:37] It is a fearful thing to love what death can touch. I'm going to try this again. Hopefully, Chitra, you can figure out this is not a good idea to ask me to do this stuff. It is a fearful thing to love what death can touch. A fearful thing to love, hope, dream to be and oh to lose. A thing for fools this and a holy thing. A holy thing to love. For your life has lived in me. Your laugh once lifted me. Your word was gift to me. To remember this springs a painful joy. It is a human thing love a holy thing to love what death has touched. Hey, Ben, it's all yours.

[00:06:29] **Dr. Benjamin Greenberg:** Thank you, Sandy. So obviously, none of us would be here today if it wasn't for the work that Sandy and Pauline did all those years ago bringing together a community. And I'm one product of that community. And we're thrilled to have everybody here on our campus today. And hopefully this will be a helpful and hopeful day for everybody.

[00:06:57] One thing I want to point out after Sandy's remarks is a lot of times these symposiums, the thought is, the focus is on education and discussion, and knowledge. And I'd actually say that's only probably about 10% to 20% of the reason we're here today. The overall majority of the reason we're here today is about building community. While there'll be lots of discussions from people who have spent their professional careers working in rare disorders, what we really hope for are the interactions between those professionals and yourselves, and amongst yourselves.

[00:07:31] When I got into this field, my mentor Douglas Kerr used to say that he felt really bad for his first 50 patients because they taught him a hell of a lot more than he taught them. And it was a very honest statement. I have a picture of Douglas from the last symposium we did here in Dallas and I was sitting in that back row there, and Sandy and Doug were sitting in the middle. And I looked over and had to snap a picture because there was Sandy smiling that glowing smile he has of just happiness and being here, and the symposium was going well. And there was Douglas Kerr flipping the middle finger at me.

[00:08:16] And so I have that photo - this is a true story. I have that photo blown up in my office and it sits on a wall over my left shoulder. So, if I ever turn around for my computer, there's Sandy being supportive and my mentor flipping me off, and it's really the community we have which is one of that level of closeness. And it really is something that's unique to the rare disease community. It's very different than other conditions.

[00:08:44] So the point of symposium today is to get together to exchange ideas. And as Doug did for us to learn from you, hopefully, just as much as you learn from the speakers and the presenters today. So we've broken up today into a variety of different sessions and we tried to balance opportunities for learning and opportunities for discussion. We're going to be starting off the morning with a talk just to set the stage by my colleague Kyle Blackburn around all these different diagnoses.

[00:09:14] Everybody comes to this room with different titles, if you will. Some of you are patients, some of you are caregivers, loved ones, some of you are clinicians, some of you are scientists, some of you are patients' advocates, some of you have been labelled with the diagnosis transverse myelitis, some with acute disseminated encephalomyelitis, AFM, MOG, NMO, all these letters and Dr. Blackburn is going to give us a foundation about how to think about all these conditions. And then we'll go to a discussion between Michael Levy and myself before having a break.

[00:09:47] Later in the day, there'll be small group discussions and opportunities for everybody to network and talk amongst yourselves. So we look forward to the interactions both in the room and outside the room.

Before I go any further, I do want to make sure that a series of thank yous occur and you're going to hear me do this a few times today. So first, and obviously to the SRNA, to Sandy and Chitra, and GG, and Roberta, and the entire team that put this together. We could not have done it without them. And we have an incredible debt of gratitude.

[00:10:21] Four sponsors for today, Alexion, Horizon, Genentech, and UCB. There are booths out front if you can go by and just say thank you. Getting patients together and getting families together in this forum take support and we are extremely grateful to them for their support. And then on the UT side, I have to thank Paula Hardiman who took the lead in organizing everything on our end. And if you've heard the term herding cats, herding clinicians at UT and other organizations is like herding drunk, rabid cats. It's not easy to do and Paula did it with ease and grace, and we're very grateful to her.