

# Welcome, Day 2

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[00:00:00] **Roberta Pesce:** Good morning, good afternoon, good evening to everyone who is joining us today on our second day of the 2021 RNDS. Today, we will be focusing on symptom management, but before diving into the talks, we would love to share a couple more “This is Me” stories with you. If you would like to share your story, please head to the SRNA expo booth, and we will be happy to help you during the entire course, of course, of the symposium. That is all for now. Please enjoy the stories and I'll see you soon. Bye.

[00:01:21] **Allen Rucker:** “It's like an anvil fell out of the sky, went through the roof, and hit me in the back. It was that sudden. What I remember was I was lying in bed thinking I maybe had a cold or something, and I felt this horrible pain around my middle, just out of nowhere. Over an hour and a half, I became weaker and weaker and weaker, and I fell on the ground and that's when I really panicked and called the doctor. He said, call the emergency people, the EMT people.”

[00:01:51] **Ann-Marie Rucker:** “When I got in front of our house, he was being wheeled out and it was just a shock. And I looked at him and his eyes were like saucers. Like, I don't know what is this?”

[00:02:07] **Allen Rucker:** “A neurologist came in and he immediately knew what it was. It's called transverse myelitis. It's a little bit like MS, but it presents itself or occurs differently. And somehow my immune system messed up and attacked my spine.

[00:02:31] I was in mourning for a long time. I lost half my body. I lost my legs. It was like I had to wait around for each brain cell to kind of accept this thing. Friends were very good, and they brought food, Alfred Hitchcock movies, stuff. But I've also found that there were people who didn't come, who didn't call, who didn't write letters, which struck me as really strange until I realized that, first of all, there are people who are scared of hospitals, but there are people who are mortified by something like this happening to someone they know, and their reaction is just not to think about it, to withdraw. Ann-Marie and I had some tough times because this was such a shock.”

[00:03:19] **Ann-Marie Rucker:** “This was not anything I expected. You work hard and everything will fall into place. Well, it didn't.”

[00:03:29] **Allen Rucker:** "And then we realized this is it, this is our reality. So, we've had to change our life accordingly."

[00:03:37] **Ann-Marie Rucker:** "We had such laughs over it. I actually think humor is what kept us together. There's a lot of dark humor that comes with dark events. And if you can laugh at it, that is the best laugh in the world. We've both found a little humility and empathy for others."

[00:04:02] **Allen Rucker:** "There is this phenomenon called post-traumatic growth where people often, right after tragedy, reinvent themselves and grow. As opposed to falling apart. I changed careers. I used to be a television writer, but my work was kind of sporadic. Instead of making television shows. All of a sudden, I started writing books.

[00:04:30] People would see me in this situation, and they'd go, 'Oh my God, if that happened to me, I'd lose any interest in life, I'd crawl up in my bed and stay there.' The truth is you have a lot more grit that you think you do. Option B is to realize you're reinventing yourself and there's no rule book. There's no guide. It's going back to life."

[00:05:12] **Olivia Hanson:** "My name is Olivia Hanson. I live in Caledonia, Michigan. I am eight years old, and I was diagnosed with AFM when I was six. When I was first told that I had AFM, I was scared. I remember all I wanted to do was walk again. AFM has changed my body because my right arm is weaker, and my left leg is weaker. In the beginning, I couldn't breathe on my own, get dressed, sit up, walk, or move on my own.

[00:05:48] I used to have to wear a back brace and I still have to wear a leg brace. It's not that hard to concentrate at school, but I do have to take medication. Sometimes I feel different from my friends, but not always. I cannot run that makes gym class hard sometimes. I am slower at doing things, but I have a really good friends that wait for me all of the time. I also feel different because I have to wear a leg brace. I feel like people stare at me when I wear it. In gym class, you can kind of tell. I get scared to tell people that AFM, about AFM because it makes me cry sometimes.

[00:06:45] I want to have my differences sometimes because I feel people treat me different, especially when I am in my wheelchair or wearing my leg brace. When people ask me about AFM or my disabilities, it makes me mad, and I don't like it at all. I just want people to treat me like normal. Normal to me means just a normal person. My name is Olivia Hanson. I have AFM and this is me."