

Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: <https://reachmd.com/clinical-practice/neurology-and-neurosurgery/beyond-the-typical-understanding-rett-through-lived-experience/57124/>

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Beyond the Typical: Understanding Rett Through Lived Experience

Announcer:

You're listening to GLC on ReachMD. This activity, titled "Beyond the Typical: Understanding Rett Through Lived Experience" is provided by Global Learning Collaborative.

Dr. Gu:

Hi. My name is Dr. Payal Gu. I am a pediatric neurologist and sleep physician at Children's Hospital Los Angeles. Today, I have the pleasure of speaking with the mother of my patient Hannah. Welcome, Suzanne.

Suzanne:

Hello. Thank you for having me.

Dr. Gu:

So, Suzanne, tell us a little bit about Hannah.

Suzanne:

Hannah is 28 years old, was diagnosed with Rett syndrome at the age of 3, and Hannah loves Disney movies, and her favorite thing to eat in the whole world is French fries.

Dr. Gu:

So what's been the most challenging about where Hannah falls in the heterogeneous nature of how Rett can present?

Suzanne:

I think the biggest difference is—and again, I want to come from a place of privilege; I'm super happy that we don't have it the other way—but with not having as many of those severe symptoms, we don't have the care; we don't get all the services.

Yeah, so she was walking, and she did maintain it. And it's one of the things that I know has—well, that I know has made all the difference. As kind of what doctors say, if you can maintain this mobility, it's just better for her in the long run. And I think that that is what has helped us the most in Hannah not experiencing a lot of the other more complicated medical problems that come from Rett syndrome.

I kind of say we're really lucky in the unlucky bus. Like, we're really unlucky in that we had this genetic mutation, but Hannah really does have a higher-functioning ability with Rett syndrome. She's mobile. She's able to use her hands somewhat. It's not fully functional use by any means, but she can hold things, and she can bring a cup to her mouth, and she eats. She doesn't need a feeding tube. We don't have significant medical problems. We've never had to wear a shaker vest or things like that. So I know that we're really lucky in terms of having a child with Rett syndrome.

When Hannah was younger, there was this thing called the Medicaid waiver, and I didn't know what that was, and parents were talking about, "Oh, you don't have diapers provided, you don't have wipes provided, and you don't have all of these things." I'm like, "What are

you talking about?" Because Hannah didn't have these severe medical problems and didn't require a nurse to be on-site all the time or have in-home healthcare, things of that nature, we just didn't get some of those other services. Because Hannah doesn't have regular medical problems, we probably don't go to the doctor nearly as much as other Rett parents, which is great. I think that's fantastic.

So there's just not as many services available to us, and it's harder to kind of get some of those services because we fall in a gray area.

Dr. Gu:

Well, thank you so much, Suzanne, for joining us today. It was a pleasure to speak with you.

Suzanne:

Thank you so much for having me. I really appreciate it.

Announcer:

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