

Transcript Details

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ReachMD

www.reachmd.com
info@reachmd.com
(866) 423-7849

Navigating Change: Transitioning Care Across the Rett Lifespan

Announcer:

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Dr. Gu:

Hi everyone. My name is Dr. Payal Gu. I am a pediatric neurologist and sleep physician, and today I have the pleasure of speaking with the mother of my patient Hannah. Welcome, Suzanne. Thank you for joining us.

Suzanne:

Hello. Thanks so much for having me. I'm Suzanne.

Dr. Gu:

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

Suzanne:

Hannah is my youngest child. Hannah is 28 years old now, was diagnosed with Rett syndrome at the age of 3, and Hannah absolutely loves Disney movies. It's her favorite thing in the world, and French fries.

Dr. Gu:

That's lovely. Thank you. So we would love to know, what do you feel changed the most as Hannah moved into adulthood?

Suzanne:

Two big things. One is finding adult care. When we were living in Portland, we live near a Rett clinic and had great pediatric care throughout her entire life, and we had Kaiser at the time—and the clinic wasn't within Kaiser—but so we just had the same care throughout, lots of support services such as OT and PT and speech pathology and all of those things. And we also had all of those things through the school system.

And becoming an adult and aging out of the school system, aging out of pediatric care, there are no adult Rett clinics. There are no adult doctors who really know about Rett syndrome, and there are no longer just centralized services.

We just really lost all that continuity of care, and I wasn't able to find adult doctors who really know anything. So that was the biggest challenge and remains the biggest challenge.

And the second was getting legal guardianship of Hannah. And always being that through her entire lifetime, having just to be the one that makes all the decisions and knows all the stuff and all the things, and you would think there would just be a very simple process, like the world would just see like Hannah's not able to care for herself, so here we go, Mom, you do—and it's not like that at all. And even for someone like myself who's just—I'm highly educated. I know how to do things, I thought I could handle this, I can fill out paperwork, and I can do this. And every year I get the Facebook reminders of me sitting outside the courthouse just crying, saying, I don't know what I'm

doing, no one will help me. And I had to hire an attorney, and it cost a buttload of money to go through that process because it's just really challenging.

Dr. Gu:

Wow, that is a lot. Thank you for sharing that with us.

So shifting gears, what has your experience been like with trofinetide?

Suzanne:

When we were first prescribed trofinetide, it was by a neurologist, and it was at the highest dosage. So 60 mL two times per day.

I was like, oh my gosh, we're doing this. I don't know what's going to happen, but absolutely a first medication that might treat any symptoms, this would be amazing.

We started the highest dose because that's Hannah's weight limits, so the other doctor prescribed her just the 60 mL twice a day. And we just had poop all the time. Just poop everywhere. And so that was not fabulous. And so we have since come down.

Everyone always asks, "What changes have you noticed?" I would say I do believe that there has been a positive progression. We see more presence from Hannah, just a little bit more eye contact, a little bit more awareness of who's in the room. Somebody walks in, Hannah will turn to the door and see who it is. Those kinds of things.

I think there's slightly less anxiety. I think that she's a little bit more tolerant of things. Not to say she just still doesn't have meltdowns or get really pissed off about things because she does. And I kind of had that same kind of thing, like just a little bit more awareness, a little bit more presence, a little bit more just "in the room" is what I think.

Dr. Gu:

Yeah that's hard. But it's great that you've come at it with such an open mind and really just trying to learn to see what's best for you, for Hannah.

So thanks, Suzanne, again for joining us for this program.

Suzanne:

Absolutely. Thanks for having me.

Announcer:

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