

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/menstrual-health-in-rett-syndrome-navigating-complex-needs/57128/>

ReachMD

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

Menstrual Health in Rett Syndrome: Navigating Complex Needs

Announcer:

You're listening to GLC on ReachMD. This activity, titled "Menstrual Health in Rett Syndrome: Navigating Complex Needs" is provided by Global Learning Collaborative.

Dr. Gu:

Hi everybody. Today, I have this wonderful pleasure of speaking with the mother of my patient Hannah. Hi, Hannah. Welcome, Suzanne.

Suzanne:

Hello. I'm Suzanne, and this is Hannah. Hannah is 28 years old and was diagnosed with Rett syndrome at the age of 3. Hannah loves everything Disney, like right now she's wearing a Lilo and Stitch shirt, and her favorite food is French fries. She's like, "What am I doing? Mom? Can I go back to my movie?"

Dr. Gu:

Perfect. Thanks so much for joining us, guys.

It's a very difficult topic but such an important one when parents are dealing with the transition of starting menstruation periods. What was that like for Hannah? And we'd love to hear.

Suzanne:

So Hannah started her menstrual cycle when she was 11 years old, so fairly early. And my understanding at the time, what doctors tell me, is that's not that uncommon in the Rett syndrome world. And I'm like, great, just one more thing.

So already we have all of these difficulties, all these complications. Hannah is not fully toilet trained. So in terms of, like, we already have pee and we already have poop, and now we have periods, and I'm like, are you kidding me?

And so we dealt with it for a little while, and I just don't like it because all of it, it's messy, and Hannah would put her hands down her pants, and because it's itchy and it's uncomfortable. And we are already wearing Pull-Ups. So then do we also do feminine hygiene products? There were so many questions.

And then I was just like, I don't want to deal with this. Do we have to have this? Does she have to experience her period? Could we use a form of birth control so that she doesn't have to have her period?

And so we talked with the doctors at that time, and I tried to ask about side effects and things like that, but we decided that she would get this shot. So we would only need to get that every 3 months.

Here's something they don't tell you. In order to get a shot, you have to pee in a cup and prove that you're not pregnant. Well, I don't know if you know this, but our Rett girls, they don't pee on command. So then I would go in, it would be time to get the shot, and then

they'd be handing me a cup. And I'm like, "What do you want me to do with this?" And they're like, "We need you to get Hannah to pee." And I'm like, "Can't you just call her doctor? She's clearly not." And they're like, "Well, we can't take your word for it." I'm like, "But I'm Mom." So they would call and get verification from the doctor. It was very strange. And sometimes we would actually have to try to pee in a cup. So I would be holding it under her, hoping that she would pee. One time she was getting a procedure, so they just did the catheter during the other procedure, but we only did that one time because I don't want Hannah to have to deal with that kind of uncomfortability.

So then we were on the shot for a long time, which helped a lot because we had very few periods. But then she developed osteopenia. And so then we took her off the shot, and she is now on a pill regimen. And we still have to deal with just all of the mess and hassle of that and the crampiness that she gets, and she doesn't understand the whole situation. So I wish that we didn't have to do it at all, but it is something that we have to deal with once every 3 months now.

Dr. Gu:

But you found a middle ground, it sounds like.

Suzanne:

Yeah, exactly. We found a middle ground and what we feel comfortable with at this time.

Dr. Gu:

Great. Thank you for sharing that.

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:

You have been listening to GLC on ReachMD. This activity is provided by Global Learning Collaborative. Thank you for listening.