

Chocolate Everywhere

A MinneStory[™]

Paula and her daughter, Andrea, discuss life living with phenylketonuria (PKU). They share memories from Andrea's childhood that were impactful and shaped their approach to normalize the ways PKU impacted her life.



Paula: What was it like when I would drop you off at daycare, and all the other kids were – as you got a little bit older – and they were all eating whatever, you know, Bonnie from daycare put on the table for you to eat? Did that make you feel any different, or, how did you feel? We had a pretty good daycare. We were really fortunate.

Andrea: No, it was okay. I just knew what I could and couldn't have, and the kids didn't really look at me any different. It was just, "Oh, Andrea eats this and I can't. That's okay." Or, "I'm eating this and Andrea can't. And that's okay." I mean it's awkward at first, like when you're little and you're trying to like go to school. And you have to have your own lunch packed and always planning ahead and thinking, "Okay, if they're going to be eating this, what can I have that's similar?" And, whether it's school or friends' houses for sleeping over, you always have to plan ahead and you just get used to it. It just becomes the norm

Paula: I am just remembering a time when you were a toddler. And we never hid foods in the house, where, you know, sometimes, people panic and think "She can't have this, she can have this," you know. So, families and parents will hide regular foods and think that, "Well, we have to hide this because our child can't have it." Well, that's not incorporating, you know, your child into the real world. And so we never hid anything. But it was just, "No Andrea, you can't have this." But next to this was something that Andrea could have that was similar. I always made sure there was something similar for you. The one time we had candy out, like a candy dish from Halloween or something, and you got a little teeny Snickers. All the bad things for you. All the wrong things for you. And you hid underneath the kitchen table, and you had chocolate all over your face, and caramel and peanuts, and you know ... there wasn't a single thing in the Snickers bar that you could have, so I remember thinking to myself, how do I react to this? And I decided not to overreact while my insides were churning. And I looked under the kitchen table, and I looked at you and your big blue eyes and blonde hair, and chocolate everywhere. One moment I thought this is the first and only time I'm ever going to see my baby covered in chocolate, and then, the second moment I looked at you and that's basically what I said. I said, "Andrea, oh I see you under there. How was that chocolate? Did you enjoy it? I hope you did cuz that's the last time you're ever going to have a Snickers." And I took you, I cleaned you up, and I called the doctor's office. Do you remember that Snickers at all or no? You were pretty little.

Andrea: No. (Laughs.)

Paula: I wish I would have taken a picture of it because that would have preserved your one chocolate phase in your lifetime picture.

Andrea: What I would have to say that I am the most grateful for would be the fact, you know – and I've told people this – that I'm grateful for you, mom, that you have made PKU such a norm. You never pitied me. You never made it seem weird, you know. You never made me feel different. It was just, okay, this is how it is, you know. You never hid foods from me. You didn't hide what it is and what could happen, and that I understood everything, even at a young age, I understood. I owe all of that to you and I'm very fortunate and appreciative, and I love you very much and appreciate everything that you've done for me.

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