



Backstage Pass

A MinneStory

Rachel and Marsha discuss Rachel's son, Cooper, and his diagnosis of MCAD deficiency found through newborn screening. Rachel shares her story of learning about her son's diagnosis, a visit to the ER, and the opportunities that exist for him in spite of his diagnosis.



Marsha: Hi Rachel.

Rachel: Marsha!!! [laughter]

Marsha: Thanks for inviting me to this.

Rachel: Yes, it's good to have you here.

Marsha: I agree. Should we just get down to business? 'Cuz when you say MCADD, I think: Minneapolis College of Art and Design. Can you please tell me in your words what MCADD stands for?

Rachel: So, MCADD is not that. [laughter]

Marsha: I was assuming. You're seven-year-old is a Picasso! [laughter]

Rachel: I wish it was. Our lives would be different. Um, MCADD is a fatty acid oxidation disorder.

Marsha: Stop.

Rachel: Exactly. So, what does it mean?

Marsha: Fatty acid.

Rachel: Oxidation.

Marsha: Oxidation.

Rachel: Disorder.

Marsha: That doesn't spell MCADD.

Rachel: No. It's a medium chain disorder. Um, metabolic.

Marsha: Okay, I understand that, okay.

Rachel: So, how I explain it and have explained it over the years is when Cooper takes in food, his body doesn't break it down properly. It doesn't know to break it down, pull out the sugars, and store them later for reserve. So if he gets sick, not eating, has no access to a source of fuel such as beverage or substance, he can go into what's called a metabolic crisis because he has no reserve, and that metabolic crisis can be fatal if not managed properly. We spent a half a day at the University of Minnesota learning about MCADD, and she gave us, um I can clearly remember that day, she said, "This is your backstage pass to the ER."

Marsha: Oh geez, no thanks.

Rachel: Yeah, right?! And it's a letter. Little did I know that we'd be using that backstage pass the next day.

Marsha: Well, you have it, use it.

Rachel: Exactly.

Marsha: When you don't know if it's going to be fatal, and you have a backstage pass? Uh, hello, go.

Rachel: Right.

Marsha: Why not?

Rachel: Yeah.

Marsha: So, so wait, your backstage pass works for all emergency rooms?!

Rachel: Yes, absolutely.

Marsha: Oh, now that's a pass! [laughter]

Rachel: But not, like, the people that were there. The people that were there, didn't know. Like we were told to sit down and take twenty, and I was like, "Nuh nuh, I've got a letter. You need to call the U, call Kristi, call somebody, but he gets the backstage." And she wasn't going to let us back there, so I just started walking back there.

Marsha: Good for you.

Rachel: And I started looking for the nearest person that looked like a physician or a nurse, and I said, "This child has a fatal metabolic disorder. You need to help us, now."

Marsha: Good.

Rachel: And it took some prodding and poking to get into a room, but they gave us a room.

Marsha: Can he have a normal life with this?

Rachel: Absolutely. He does today, like he has been playing soccer since he was in preschool, he's been in swimming since he was six-months-old. We just have to make sure we fuel him up before those events and activities, and immediately after. So I mean he's really a normal kid other than this one diagnosis.

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