



Gabe-orade

A MinneStory

Gabe talks with his mom, Jen, about the ways he has incorporated MCAD into his life. Jen shares her advice for other families dealing with this disorder, but also the many ways they are just a typical family.



Jennifer: So what sports do you play?

Gabe: Football, basketball, and baseball.

Jennifer: Do you have to do anything special when you play football?

Gabe: Drink Gatorade. Have granola bars.

Jennifer: Okay.

Gabe: Make sure my carnitine doses are up.

Jennifer: By up, what do you mean?

Gabe: Like they aren't low, so I start puking.

Jennifer: Do you have to stop for rest breaks more often?

Gabe: Yeah, a little bit more.

Jennifer: Do you think that interferes with the game, or are the coaches pretty good?

Gabe: The coaches are pretty good with it, cuz they've known me since I was a little kid. And they know what I have.

Jennifer: How did friends at school react when they learned about your condition?

Gabe: They just thought it was kind of cool.

Jennifer: What do they call Gatorade?

Gabe: Gaberade.

Jennifer: (laughs)

Jennifer: How long have you been at that school?

Gabe: My whole life.

Jennifer: Right.

Gabe: Since I was three years old.

Jennifer: You've been at that school since you were three years old. The same school, the same teachers, the same kids. How many kids are in your class?

Gabe: 14.

Jennifer: So, they're kinda used to you, aren't they? Everybody just knows if you need a break.

Gabe: What advice would you give to other families dealing with this condition?

Jennifer: I think that with any of the disorders on the newborn screen, the knowledge is power. By getting the newborn screen back, and educating yourself, that's the best you can do.

Because the trick is with a lot of these kids is you don't know they're sick until they're really sick. And you should have been there already. You should have been at the hospital by the time they're looking like that. So, take it seriously. It's not to be taken lightly. And providers to listen. These kids look fine until they look awful. And there's a pretty fine line between they look fine and they look awful, so.

Gabe: Mhmm.

Gabe: What has helped you the most throughout this experience?

Jennifer: My husband has been – I don't know what I would have done without him. Not that we haven't had our issues, and it was really stressful when you were small, but we worked together at it and... Yeah, definitely Darrin.

Gabe: Dane not so much. (laughs)

Jennifer: Dane was a good baby. It was a good thing he was a good baby because you were a handful.

(Both laugh)

Jennifer: And now it's kind of the other way around, where you're the laid back one and he's all over the place, so. But it all works out. But no, Darrin is – I don't know what I would have done without him, so.

Presented by the Minnesota Department of Health

