



Kinda a Nice Vegetarian Diet

A MinneStory™

Joe and Becca talk with each other about their non-identical twins (Sam and Grace) who both have PKU. The twins share what living with PKU is like for them and Joe shares his approach/advice when talking with newly diagnosed families.



Joe: So, Bec, we have had a chance to meet a bunch of families that have PKU, and like new families, right?

Becca: Mhmm.

Joe: How do you talk to them, like about how our kids are, and like how do you reflect on our kids in helping them understand like what their life can be like.

Becca: Well, I think it's helpful for people to start understanding first by knowing that they're twins.

Joe: Yeah.

Becca: And they were born at 29 weeks. And they were small. They're preemies. And the funniest thing that we answer, I think happened more so when they were younger, was people found out they were twins. And it's a boy and a girl. And then their next question when they found out they had PKU was "Oh, are they identical?" Well, no, they're not identical. They're a boy and a girl." (laughs)

Joe: Yeah.

Becca: But it's hard I think for people to kind of, you know, put that together, but they're a boy and a girl. Sam is a very typical, almost 8-year-old, boy. Sam, do you want to say your name?

Sam: Sam.

Becca: And how old are you?

Sam: Seven.

Becca: Do you want to tell us, um, what PKU means to you? Like, what do you do with PKU every day?

Sam: It just kinda feels like I'm on a vegetarian diet. That's it. Like, there's a ton of unhealthy stuff that I can't have, so that's why I think it's kind of fun having it.

Becca: Is there anything else you want to say about PKU today?

Sam: Mmm, no.

Becca: And he loves Calvin and Hobbs, and video games, and reading.

Joe: Mhmm.

Becca: In fact, he got in trouble the first week of school for hiding and reading books all over the classroom. So, that's something that, you know, you have to be kind of proud of.

Joe: Mhmm.

Becca: And his twin sister, who is not identical, Grace, is kind of the opposite.

Joe: Grace, can you tell me a little bit about PKU?

Grace: Umm.

Joe: What comes to your mind first?

Grace: Uh, it's something that some people have where they can't have particular foods.

Joe: Yeah, okay. What's that like for you?

Grace: Ohhh, I don't know. (laughs)

Joe: It's just kind of normal, isn't' it?

Becca: Yeah.

Joe: What's a good thing or a positive thing about PKU?

Grace: Um, a good thing about PKU is that it's kind of a nice vegetarian diet.

Joe: Mmm. What's your favorite thing to eat?

Grace: Mushrooms. (laughs)

Joe: Mushrooms? Okay. It's just your life, right?

Grace: Mhmm.

Becca: She really likes her alone time. She loves to play by herself. She loves dolls and ponies and animals.

Joe: Mhmm.

Becca: And wants to be a veterinarian.

Becca: But going back to new families, what would you say to a family with a new diagnosis? What have you said to families with a new diagnosis? What advice have you given them or hope you've given them?

Joe: I want to know how they're feeling about it first, you know. Like what's – what are they experiencing at that time, um, partly because what I want to tell them is that it's going to be okay. And I think they've heard that a lot. And that's easy to say, but without the benefit of experience, you just have to take somebody's word for it, right?

Becca: Mhmm.

Joe: Because it's a lesson that I've learned so much, like, you know, the persistence. I want to really push that as something that they hear. Just keep going. It's going to be really hard, but you can get – you'll get used to this. It'll become second nature. But we're also really fortunate, right? Because we have a lot of people around us helping.

Becca: Mhmm. It's been really nice to sit here and talk with you about this today, Joe.

Joe: It's fun. Yeah.

Becca: I think it's fun to share our story, and it's fun to talk about our kids. I just want to thank the Minnesota Department of Health for giving us this opportunity to shed some light on newborn screening. And we think it's really important. Our lives certainly would have been a whole lot different without it.

Joe: Yeah. Yeah. And we're – I mean we know that we've – we have literally done everything that we can to give these kids a good life.

Becca: Yeah.

Joe: And it started with – yeah, of course we're going to have that screening done...

Becca: Yeah.

Joe: ...and going from there. Like, we have the information and we're able to do something about it.

Becca: Yeah.

Joe: So it's been – it's been good for us.

Becca: We're lucky.

Joe: Yeah.

Presented by the Minnesota Department of Health

