Every Label, Every Time

A MinneStory™

Sarah and her son, Evan, discuss Evan's diagnosis of galactosemia. They describe the importance of finding food that is safe for him, and how grocery shopping is no longer a simple activity.

MINNE STORIES

Sarah: I've always said that grocery shopping was my hobby, that um, I spent a lot of time reading labels in the grocery store. Um, I'd usually leave the kids at home and go in the evening and just spend a lot of time doing it, not something that I ever planned on doing but it's the way that it went. The labels and the dairy products in products, it's very frustrating just because the companies change the ingredients all the time so our rule was to read every label, every time.

Evan: Galactosemia is a metabolic disorder which means, and the simplest explanation that I can give is that my body can't break down galactose because it's missing the proper enzymes to do that. So it just can potentially cause long terms problems if I have too much because it will build up in my body, the galactose that is, and that is because my body can't break it down.

Sarah: The doctors were very reassuring. They told us that since it was caught early, um, and because of the newborn screening and being caught at days, um, that you would likely have a good outcome. Newborn screening, 3 days is kind of the perfect story. That you're identified early, you didn't get seriously ill, you were um treated right away and given healthy food. I have ended up with a network of people across the country and some of them have stories of severe disability or death of their babies and this is truly something that saved your life.

Presented by the Minnesota Department of Health

DEPARTMENT OF HEALTH