



# Amazing Little Boy

A MinneStory

During the midst of their son's medical crisis, Jenni and Adam learn through newborn screening that he has a serious metabolic disorder. Listen to their story to hear them share their experience and how time has provided a new outlook of hope and perspective for their family.



**Jenni:** Well Dylan is 2 ½ years old. And he is an amazing little boy. He is just the light of our lives. He is running and jumping and exploring the world for the first time. He's so lovable. He'll run and give you a hug and give you a kiss when you want. He is enjoying life from where he started. This is an amazing accomplishment to see where he is now because he was born with a very rare metabolic disease called propionic acidemia.

**Adam:** So, what is propionic acidemia like?

**Jenni:** It's very invisible. I mean you would never notice it on the outside that there's something wrong. It's completely happening on the inside and that's the scary part, is that it can happen at any moment. Your kid could be having a seizure, they could have brain damage and you wouldn't even know it's coming. My pregnancy itself was very uneventful. We had no indication that anything was wrong. Actually, I went four days over my due date. So, he was late even. Dylan required a very special metabolic and genetic doctor because he suspected he had a metabolic disease, and that a lot of kids don't survive this.

**Adam:** I remember there being peaks and valleys of emotions. You know, going from him potentially having a breathing issue to being – and having to be transferred to Children's – to he's just dehydrated, and then that was such a sigh – sense of relief that, you know, this is just an easily correctable issue. To then finding out that his ammonia was so high and that this was a very serious issue. That a lot of kids don't survive from was really, really hard to take, to see a 3-day-old kid have to go through this. And for us not to know what is causing this, and why our son Dylan?

**Jenni:** You're just devastated. You just, you look at your little kid that shouldn't have to go through this, shouldn't have to be this way. I mean this little baby that's only three days old, that's a part of you that you thought was completely healthy when you went home from the hospital. That they just are struggling to breathe and that they might not make it. And that you're broken in those moments when – when you don't know, and you can't do anything. I mean you can't do anything. You're doing the best you can. You don't know what it's like until you have a kid, and when you have a child and you just realize you will go to the ends of the earth and fight hell and back to make them better. I remember exactly – her name was Jody. I will never forget her. And she said, "I know this has been the worst day of your life, but I wanted to give you some good news. His ammonia was down to 90 from 1200." In like an hour. I mean like the best news you could ever hear. It cleared that fast. I mean we trust them wholeheartedly. They saved his life at three days old, and so, we did the transplant. And now he is doing amazing. I mean, people, you know, you go down the street and you're at the park and nobody has any idea what he's been through, at all. You'd never know. He's just a happy-go-lucky little boy that has no idea that going to get your labs drawn every month is not normal. And that not eating certain things is not normal. And that being on medication is not normal. That's his normal.

**Adam:** He's definitely made us stronger. And you see what he has gone through in his short 2 ½ years on this earth. And how taking medication every day is just a part of his life. And he knows no different. And he's happy. It doesn't let him bother him even when he doesn't feel well. I

think, I look up to him.

*Jenni:* You know, my hero comes in the body of a 2 ½ year-old, little red-headed sweet boy. I look back on what we were 2 ½ years ago, scared out of our minds, hearts broken, just had no idea what the future held. And if I could, I wish I could go back to myself or go see those parents at that time now and tell them that you'll get through it. You know, your new normal. You'll get through it, and it'll just become your life. And to never give up hope.

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