

“I will never get it perfect. I can’t protect him from everything. That has been really hard for me to surrender to.” —Julia



Be prepared for Conor’s high five—it will throw you back a few steps. He is taller and more solid than most two-year-olds and his hand connects with the force of his exuberant personality when anyone offers the opportunity. “Conor, high five!” his dad, Daryl, says, holding his own large hand aloft, and Conor charges over with excitement. “Say Happy Day,” his father instructs, and with a smile that fills the room, Conor complies. “Hap-py Day!” he says, whacking his little hand into his father’s.

Conor was born big—a hefty nine pounds. He emerged “Chubby and bright eyed,” his mother, Julia says. “We had no clue that there was any issue until we got his newborn screening results back.”



The call came from their doctor at 11 p.m. “My heart just about stopped,” recalls Julia. “She said, ‘How’s Conor?’ and I said, ‘Well, he’s asleep, so I think he’s fine.’ She told me that he had tested positive for Maple Syrup Urine Disease (MSUD) and that we needed to stop feeding him, and get him to the hospital, immediately.”

“We were aware of the disease,” Daryl says, who, as a member of the

Mennonite community, knows that one in ten Mennonites are carriers of MSUD. “But we had no idea what it would entail.”

“We drove him to the hospital right away,” Julia recalls. “He was screaming—he wanted to eat. I was sobbing.” At the hospital they immediately started an IV. When Julia and Daryl stepped away for a moment to collect themselves, Conor stopped breathing. “Of course at that point I completely lost it,” says Julia. “I came back and there were 15 people all around him.” Having lost a daughter to anencephaly a few years earlier, as well as suffering a miscarriage, Julia and Daryl had already experienced more than their fair share of loss. They were determined to do everything in their power to help Conor survive.

Luckily the doctors were able to get Conor breathing again, without any damage to his brain. The EEG showed healthy brain development in general, and Julia and Daryl were told that they could continue to keep Conor’s brain healthy if they strictly monitored his protein intake. Ninety-percent of his diet would have to be medical formula, with the remaining 10% foods that had little to no protein. It would be a constant balancing act to make sure Conor was getting the nutrients he needed to grow without overloading his system with the three amino acids found in protein that his body couldn’t metabolize, leucine, isoleucine, and valine.



“It was definitely information overload,” Daryl shares. “The

doctor would draw pictures to explain what we needed to do. We'd have ten new questions each time we went back. We were so afraid we wouldn't do it right. We always had to be thinking: What did Conor eat today? What else can he have? Everything has to be measured out. We learned how much leucine is in a quarter cup of rice, how much leucine is in a pretzel."

"It was overwhelming at first," agrees Julia. "But now I can do it and have a conversation at the same time—it becomes routine."

Now the most difficult thing about monitoring Conor's eating is explaining to him why he can't eat the foods the rest of his family can. "He loves to eat," Julia says. "And he's at an age where he wants to be like us. Mealtimes are hard."

Conor has to be watched around food because he is tricky and smart. There was a day that the family refers to as "The Cheese Incident" when Conor nabbed a block of cheese from the fridge and took it to one of his favorite hiding places. "He ate the whole thing!" Julia recalls. "It sent him into this drunken state, stumbling around, incoherent, vomiting. I couldn't sleep for I don't know how many nights after that, blaming myself."

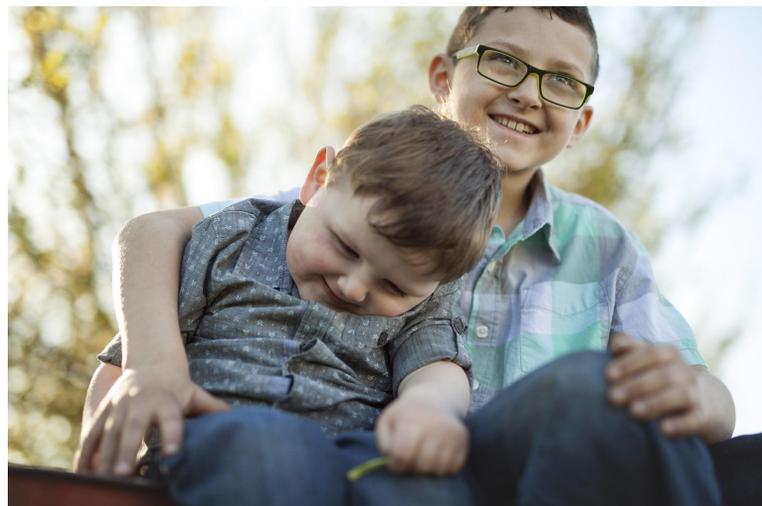
"It's really hard for me to be okay with the fact that I cannot get this perfect," Julia reflects. "I want to get his food exactly right for him, the levels he needs one-hundred percent exact, but I can't. I'm not his liver. I will never get it perfect. I can't protect him from everything. That has been really hard for me to surrender to."

"It's been a journey to accept that it's okay that it's NOT okay," continues Daryl.

Conor picks up a ball and throws it across the room, the force of his throw launching him backwards onto the floor.

"Ow," he says cheerfully, and squirms to standing again, charging across the room after the ball. Julia laughs. "When he's in the hospital the nurses will say, 'He doesn't seem sick, he's still moving.' We say, 'He moves ALL THE TIME.'"

Luckily, Conor has his two older brothers, John and Eric, as well as two rambunctious dogs to keep his energy levels





high. His eldest brother, John, who is nine, gives Conor piggyback rides whenever requested, and one dog will happily let Conor into his kennel where the two of them will hang out for long stretches of time.

“His condition draws us together,” Julia says. “There are multiple times when we have had to lay him on the altar and say ‘Okay God, he’s in your hands.’ And we trust that God really is doing what he needs

to. We are blessed with Conor, and he is in God’s hands.”



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