

One Child's Struggle with Enteric Hyperoxaluria

Aidan's Story



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– Jason Simecka

Just 12 weeks pregnant with their second child, Jason and Dori Simecka were told there was something wrong with their baby. A routine blood test revealed that either their baby was developing without a brain, without a spinal cord, without both, or there was something wrong with the abdomen. The Topeka, Kansas couple immediately began praying it would be the baby’s abdomen.

An amniocentesis was performed, and 21 long and excruciating days later, the message from the lab in California revealed there was something wrong with the baby’s abdomen. The boy’s intestines were outside of his body and floating within the umbilical cord, medically known as an omphalocele.

Aidan Paul Simecka was born seven weeks premature in July 1996 by c-section. At birth, he was diagnosed with Beckwith-Weidemann Syndrome, a rare growth-related disorder with a range of over 30 different types of abnormalities. “There were so many doctors I’m not sure which one said this to me, but we were told that if we had to pick a birth defect for our child, this would be the one. In most cases, every abnormality could be surgically repaired and he should be out of the woods by age eight. We began

to anxiously await his eighth birthday,” says Dori.

Aidan’s omphalocele was repaired at 10 days of age. At one month old, Aidan suffered a bowel obstruction that perforated, a complication from his previous abdominal surgery. He underwent yet another surgery, during which a portion of his intestine was removed. Unfortunately, surgery was not enough for Aidan to rebound. He became severely septic and his kidneys began to shut down. “I remember thinking about the phrase ‘as white as a ghost’ as I looked at my son lying in the NICU at Children’s Mercy Hospital in Kansas City, Missouri. Aidan’s skin was as white as the sheets he lay on. All the doctors would say to us was that we had a very sick little boy. I remember the nurse, who had spent three entire days trying to hook Aidan up to the hemodialysis machine, finally breaking down in tears in front of us. It was his last chance and this had to work. We knew it and the medical staff knew it, too,” recalls Jason.

The next four years were ones of inescapable stress—an emotional and physical roller coaster for Dori, Jason, their then two-year-old son Avery, and the extended family. It was a life-threatening roller coaster for Aidan.

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Ten surgeries later, Aidan celebrated his eighth birthday. While undergoing his last abdominal scan to check for Wilm's Tumor of the kidneys, a cancer associated with Beckwith-Weidemann Syndrome, doctors discovered he had kidney stones. "He was eight-- the magical age we had been holding on to for so long and now doctors were saying he had yet something else wrong with him. It was hard to hear," Dori recalls.

In 2004, Aidan and his parents traveled to the Mayo Clinic in Rochester, Minnesota to meet with nephrologist Carla Monico. After many medical tests and a liver biopsy, Aidan was diagnosed with Enteric Hyperoxaluria, a silent and life-threatening kidney disease. The bowel resection Aidan had undergone as an infant triggered his body to begin hyper-absorbing oxalate. Oxalate is the salt form of oxalic acid which is a natural end-product of metabolism normally excreted from the body. Those suffering from Hyperoxaluria have too much oxalate in their bodies and it begins eating away at the kidney tissue and causes kidney stones to form.

Aidan currently suffers from reduced kidney function. Eventually his kidneys will shut down and he will need

a kidney transplant. Unfortunately, a kidney transplant will only buy Aidan more time. Unless a cure is found, Aidan's body will continue to hyper-absorb oxalate even following a transplant. Aidan's kidneys are not the only organ that may be affected by the disease. Oxalate can build up in the blood and deposit in the eyes, heart, bones, and other major organs and tissues causing additional painful, life-threatening complications.

In the meantime, Aidan drinks two liters of water a day, takes medicine for his kidneys five times a day, avoids drinking soda and eating salty and fatty foods, as well as foods high in oxalate. He also visits the Mayo Clinic every six months where he is a model patient, enduring whatever his doctors ask of him.

Despite all these challenges, Aidan lives a very active life similar to that of any other adolescent boy. He doesn't keep his room very clean, he plays baseball with great intensity, he makes people laugh, he has braces, and he "forgets" to do his chores on a regular basis. "I'm just a regular kid," says Aidan. "The only thing people might notice about me is that I carry this big water jug everywhere and I get to miss school more than my friends because

I have to go to the doctor a lot. One time my mom scheduled me to go to Mayo on Spring Break so I wouldn't miss school and I was like NO WAY! She changed the appointment."

Aidan is currently in the seventh grade at Washburn Rural Middle School in Topeka, Kansas. He is the nephew of Anders Bergkvist, Head Tennis Professional at Allegheny Country Club in Sewickley, Pennsylvania, and his wife Brandi. Aidan and his extended family are looking forward to the day a cure is found for Enteric Hyperoxaluria, so that Aidan and so many others no longer have to live in fear of this disease. They count their blessings every day, never taking for granted the miracle of Aidan's life.