

# A Lifelong Need

Five year old Ryan Still of Madison, New York has a hole in his chest. It's a small opening where his doctors insert a catheter to administer regular blood transfusions and plasma exchanges, a process where his plasma is extracted from his whole blood and exchanged with fresh plasma. Ryan needs these blood products because he has Atypical Hemolytic Uremic Syndrome (AHUS), a rare disease that destroys his red blood cells causing toxins to infiltrate his blood stream, attack his kidneys and ultimately promote kidney failure. The cause of AHUS is unknown and there is no cure. For Ryan and his family, living with AHUS means routine hospital visits, numerous daily medications, regular blood transfusions and waiting for a cure.



In July 2002, Ryan was just three years old when he developed a stomach illness that persisted for ten weeks. His doctors advised his mother, Heather Still, that Ryan merely had a stomach virus and sent him home to rest. But when Ryan grew increasingly lethargic later that night, his mother rushed him to the emergency room at SUNY Upstate Medical Center in Syracuse where doctors found he had a low blood platelet count, low blood iron count and elevated renal functions. Something was drastically wrong—his kidneys were failing him.

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That same evening, doctors diagnosed Ryan with AHUS and immediately placed a catheter in his chest for plasma exchange procedures. For the following five days, Ryan endured routine dialysis and one plasma exchange per day while in the intensive care unit. Three weeks later, Ryan finally went home. Since then, his health has hit dramatic highs and dangerous lows. “Ryan has been forced to live the life of an adult,” says Heather. “We travel two hours to the hospital three times a week, on average, where Ryan patiently undergoes three hours of doctor visits and three hours of plasma exchanges.” During the last two years, Ryan has received ten whole blood transfusions and more than 240 plasma exchanges. He will need these transfusions and exchanges for the rest of his life.

“This is the hardest situation for a family to experience,” says Heather. “The doctors don’t have all the answers to our questions and the future is so unsure. We take comfort in knowing that with the help of routine blood transfusions and plasma exchanges, Ryan can maintain his health and live as normal a life as possible.” Today, Ryan is a playful young boy who “shows the world he is going to beat this illness,” says Heather. “He wakes up each day and knows he’s sick but he doesn't let that stop him. I ask blood donors to take the time to give blood, to continue helping save the lives of people like my son and the countless other patients in need out there.”



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