

Losing Stacia

One Mother's Story

In January of 2004, Stacia Mabry, a 17-year-old honor student at Plainfield High School, was looking forward to a trip to Washington DC for a Native American Youth Summit. One month later she was in a hospital room in Hartford dying of Wilson's Disease, a genetic disorder of the liver.

"She had such plans for her future," says her mother, Susan Griffin. "She'd been accepted at a pre-med summer school program and was going to be a doctor."

Stacia was the oldest of Susan's four children, and Susan always thought of her as the healthiest. But Stacia returned from her Washington trip feeling tired, and with little appetite. Susan suspected that her daughter had picked up a bug. But 24 hours later, Stacia was jaundiced, and so weak that when she tried to walk from the bathroom to her bedroom, she collapsed in her mother's arms. Much to Susan's horror, Stacia's condition worsened by the minute.

Stacia was taken to Backus Hospital in Norwich where she underwent a battery of tests, all of them inconclusive. Within three days she was put on a respirator. Her doctors made a decision to send Stacia to Connecticut Children's Hospital, where she was flown via LifeStar.



The Mabry/Griffin clan. From left, Stacia, Shelby, Colton, Susan and Carney; up front, Allen; back row, Howard.

On February 12, five days after being admitted to the hospital, Stacia turned 18 in the ICU. The following day, Dr. Donna Zeiter identified Stacia's mysterious illness: Wilson's Disease, a rare

genetic disorder that renders the liver unable to process copper. Susan learned that, unbeknownst to anyone, copper had been building up in Stacia's liver since the day she was born. "It had simply hit critical mass," explains Susan. "Copper was being excreted all over her body – first the gall bladder and the stomach, then the kidneys."

Because Wilson's Disease interferes with the blood's ability to clot, a liver transplant would have been risky, but it was a chance that Stacia and her family was willing to take. It was her only hope for survival.

Stacia was transferred to Hartford Hospital, and for a time was the number one candidate on the liver transplant waiting list. However, even though Stacia's blood type was simple to match, no donor was found. "The days came and went while I watched my daughter go downhill," Susan recalls. "I called TV stations for media coverage and was shot down. How dare they? This was my baby and there was no one to help me."

Stacia was rapidly becoming inoperable. She was on continuous dialysis, her urine was black, and her skin and her eyes were a deep coppery color. By the early hours of March 7th Stacia was septic, bleeding from her nose and mouth.

"There was no turning back," says Susan.

Later that day, Stacia Mabry was taken off life support and succumbed to Wilson's Disease.



Stacia at 17.

Susan Griffin is a member of the Mohegan Tribe, as was Stacia. (In fact, Susan's great uncle was the last full-blooded Mohegan chief.) She doesn't know if Wilson's is more prevalent among Native Americans; it's one of the many questions she has about the disease. What she does know is that it's caused by recessive genes from both parents; it strikes one in about 40,000 people; and it can be diagnosed by a simple blood test. (For more information about Wilson's Disease, turn to page 8.)

That blood test determined, thankfully, that her three surviving children are not afflicted by Wilson's.

Susan is coping with the loss of her daughter as best she can. She went back to work almost immediately, diving into her job as Applications Manager of Integration in the Information Systems department of the Mohegan Sun, and caring for her three children, her stepdaughter, and her husband. "I've had to be the center of gravity for my family," she says.

The rest of her time is dedicated to raising awareness about Wilson's Disease and spreading the word about the importance of organ donation. On March 30th, just weeks after Stacia's death, she told her devastating story to a room full of rapt listeners at Flavors of Connecticut.

"Some people worried that it was too soon to speak about my daughter," she recalls. "But I'll never keep quiet about this."

Gifts in memory of Stacia Mabry may be made to the CT ALF, 127 Washington Avenue, North Haven, CT 06473.

Donations to ALF promote the prevention, treatment and cure of diseases of the liver, including Wilson's Disease.