

MARLAINA'S STORY

A real case demonstrating
the unfairness of damage caps.

Marlaina's Story

Eight-year-old Marlaina kept getting sicker and sicker as ammonia built up in her bloodstream. Her condition was treatable, but a key test to investigate the metabolic disorder that Marlaina had was never performed. The test was done too late for Marlaina, who died a slow and agonizing death.

At eight years old, Marlaina was a petite, perky bundle of energy. She raced from dance lessons to her gymnastics classes, which she loved, and then was off and running to her Brownie troop meetings. She had no less energy in school, where she did very well. Even at her young age, Marlaina had plans to go college, have a career, and find time to be a wife and mother. With her level of energy, her mom and dad had no doubt that she could do it all.

Marlaina was not just an energetic little girl. She was an excited one. Marlaina, who was a little sister to her brother, was about to become a big sister. She couldn't wait to see the new baby. In July, Marlaina's little brother arrived. Her warm, loving and very close-knit family became even closer with the arrival of the little guy. That summer was a happy and exciting time in Marlaina's home.

Just two months after her baby brother was born, Marlaina became strangely ill. When she woke one morning, she was talking in a confused and disoriented manner. She was restless and then became combative. Her mother, who for several years was employed as an RN in the intensive care unit at one of Pennsylvania's best hospitals, was very concerned about Marlaina. She immediately took Marlaina to a major hospital in their community.

Initial testing at the hospital showed that Marlaina had high levels of ammonia in her bloodstream. Marlaina's mother and her doctors were very concerned about this result. Ammonia is toxic to the brain if it is present in the bloodstream in high amounts for too long. One of the conditions that could cause a patient to have high levels of ammonia in her bloodstream is a defect in the patient's internal metabolism, for example in the patient's ability to break down food substances. Marlaina's mother thought that her daughter might have such a problem because Marlaina had an intense dislike for any food with protein. She asked the doctors whether Marlaina might have a metabolic disorder. She was told that Marlaina had been tested for such disorders, but nothing had been found.

What Marlaina's mother was not told was that the doctor in charge of Marlaina's care had failed to order the single most important lab test to detect metabolic diseases.

Over the next few weeks, the family stood vigil over Marlaina as the ammonia continued to ravage her body. Her father was in the hospital with her every day. Her mother, despite having a new baby at home, never left Marlaina's side. She slept in Marlaina's room each night and even had her new son brought to the hospital so that she could nurse him without leaving Marlaina's side. Marlaina's mom and dad talked to their daughter, sang to her, held her close, stroked her hair, read to her. They prayed. Marlaina got no better.

After two weeks in the hospital, another of Marlaina's doctors made a startling discovery. In reviewing the chart, he discovered that the key test to investigate for a metabolic disorder had never been performed. Immediately, this physician ordered the critical test. The results came back positive. Marlaina had a metabolic disorder. Her physicians immediately began dialysis to rid her body of the toxic ammonia.

Two weeks had already been lost because of the failure to perform the critical test. By the time that her physicians began treating the disorder, it was too late. Marlaina's brain was already severely damaged. She became sicker and sicker. Her small body became unrecognizable. Gradually all of the vital organs of her body shut down—first her kidneys, then her lungs and finally her heart. With her parents at her side, as they had always been, Marlaina breathed her last breath and died. Her mother was still clutching her small hands as the life left her.

It had been over a month since Marlaina had first been admitted to the hospital. She had died a slow, agonizing death, a little bit each day of that month.

After Marlaina's death, all of her medical records were reviewed by a specialist from one of the country's leading children's hospitals. This specialist said:

Overall, this appears to be a tragic case of a patient with a treatable condition, who presented with very typical findings of her disorder, but was misdiagnosed and not provided with appropriate therapy. Her condition was allowed to deteriorate to the point at which no treatment could have been effective. Her family had every reason to expect that she should have been able to receive appropriate care in a children's hospital equipped with a pediatric intensive care unit and staffed with a full range of pediatric subspecialists. Unfortunately, this did not turn out to be the case, and she lost her life as a result.

None of this had to happen. This gut-wrenching grief, this devastating loss could have, and should have, been avoided. One simple test would have revealed the cause of Marlaina's high ammonia levels and then the appropriate and effective treatment could have been provided. That test was not done until it was too late. Marlaina and her family have paid the ultimate price for that mistake, even though the mistake was not theirs.

Should Marlaina's parents, whose grief and sense of loss is not limited, be limited to a damage cap of \$250,000? Does this number even begin to compensate them for watching their only daughter die a slow and agonizing death? Would it be fair for you if this happened to your eight-year-old little bundle of life and energy?



At age eight, Marlaina was full of life and anxious to be a big sister. But when she got very sick, a doctor failed to perform a key test for metabolic diseases. As a result, she suffered severe brain damage from too much ammonia in her system and died.