

CAROLINE'S STORY

A real case demonstrating
the unfairness of damage caps.

Caroline's Story

Little Caroline was born pre-term and was at an increased risk of developing high levels of bilirubin. Her medical condition could have been easily prevented, but Caroline's doctors failed to recognize and treat her excessive bilirubin levels in time, resulting in severe brain damage. She is blind and profoundly disabled and functions at the developmental level of a one- to four-month-old child even though she is now 11 years old. She also suffers severe orthopedic problems and has endured painful surgeries and treatment.

Caroline was welcomed into the world by her mother, Kathleen, on Tuesday, September 21. Caroline was Kathy's first child, and the 34-year-old was ecstatic that her first child was a baby girl. Kathy had a very close relationship with her mother, and she was looking forward to that same, very special mother-daughter bond with Caroline.

Kathy's pregnancy had been uneventful and normal in all respects. She was quite surprised, therefore, when her water broke at less than 36 weeks. She had expected to deliver after the usual 40 weeks of pregnancy. She immediately went to a Delaware County Hospital, where she received antibiotics so that she and her baby would not develop an infection because of the premature water-breaking. Later that night, Caroline made her appearance. Caroline appeared to be a perfectly healthy baby. She was active and alert and all of her vital statistics were normal. Her only problem, aside from the fact that she was pre-term, appeared to be bruising of her head and face from delivery. Kathleen, though tired, insisted on breast-feeding Caroline, wanting her to have the best possible start in life.

Over the less than 36-hour admission following her birth, Caroline began to change colors, a fact noted by a student nurse in the chart and all of Kathy and Caroline's visitors. No one at the hospital appeared concerned by the change, and Kathy and her baby girl were sent home on Thursday. No instructions were given to Kathy regarding monitoring her baby's color, and no arrangements were made to have any health care provider examine the baby in the days after her discharge despite the fact that she was pre-term. Kathy was told to take Caroline to her pediatrician for a two week check-up, which Kathy arranged as soon as she got home from the hospital.

By early Sunday, Kathy noted that her baby's eyes and skin appeared yellow. By this time, Caroline was also not feeding well and was more listless and lethargic than she had been in the hospital. Kathy called her pediatrician and described all of these symptoms to her. The pediatrician did not ask to see Caroline that day. She advised Kathy to try to nurse the baby frequently, place her bed by a window and go to the hospital the next morning for bilirubin testing.

Bilirubin is a naturally occurring substance in the body. It is the waste product that results from the breakdown of hemoglobin molecules from worn out red blood cells. Usually, it is processed through the liver and excreted from the body as the chief component of bile. Excessive levels of bilirubin in the body cause a yellowing of the skin and eyes known as jaundice. This yellowing does not generally fully develop until more than 36 hours after birth. Very high levels of bilirubin in the blood system of newborn babies can cause a condition known as kernicterus, which is the staining of brain tissue, as well as the formation of brain lesions and destruction of portions of an infant's brain. Kernicterus can cause cerebral palsy and mental retardation. This condition is easily prevented by monitoring the bilirubin levels of infants and then treating infants with high levels of special lights (phototherapy) or blood transfusions (exchange transfusions).

Pre-term infants, such as Caroline, are at an increased risk for excessively high bilirubin levels. Additionally, infants who have suffered head bruising during delivery and are breast-fed, again such as Caroline, are at increased risk of elevated bilirubin levels and kernicterus. Infants who are discharged from the hospital in less than 36 hours, such as Caroline, can fall through the cracks since their jaundice may not be fully developed. Such infants, therefore, require closer monitoring following discharge, such as a well baby visit by a home nurse or a visit with a pediatrician within 2-3 days following discharge, not 2 weeks. At risk infants require even closer monitoring so that early treatment can be provided before any brain damage results to the child.

Kathy took Caroline to the hospital the next morning as instructed for the blood testing. When the blood test was over, she took Caroline home, again following the instructions of her pediatrician. The results of the testing were that Caroline's bilirubin level was 34.6. This is extremely high. Levels of only 12-15 require immediate medical attention, and her levels were almost three times the intervention levels. The pediatrician did not immediately admit Caroline to the hospital for phototherapy and exchange transfusion. Instead, she did not believe the first test results and merely ordered the test repeated that afternoon. Kathy again took Caroline to the hospital for the blood test. This time the results were even higher, 36.9. The pediatrician then arranged for Caroline to be admitted to the hospital to the care of a neonatologist. What Kathy did not know was that this neonatologist had failed to pass his pediatric board certifications on four separate attempts and had never treated a baby with a bilirubin level this high.

The immediate treatment that Caroline required to avoid brain damage was an exchange transfusion, which is where fresh blood is exchanged for the bilirubin contaminated blood. The neonatologist ordered an immediate exchange transfusion and began triple phototherapy. However, due to the delays in typing and cross-matching Caroline's blood, delays at the hospital blood bank and delays by the nursing staff, the transfusion did not begin until almost seven hours after it had been "stat" ordered by the neonatologist, over 24 hours after the pediatrician had been advised of the situation, and over four days from Caroline's color changes in the hours after her birth, which signaled the beginnings of jaundice and which was never investigated before her discharge.

Caroline has suffered severe brain damage as a result of the failure to timely recognize and treat her excessive bilirubin levels. She functions at the developmental level of a one- to four-month old child, even though she is now almost 11 years old. She is blind, has profound mental retardation, and a seizure disorder. She cannot roll over. She cannot sit without support. She cannot stand. She is entirely physically dependent. She cannot use her hands or arms to manipulate objects, hold things or feed herself. She has impaired swallowing and must be fed through a gastric tube that was surgically inserted into her stomach. She is not toilet-trained and never will be. She cannot follow commands or understand even the simplest of language, although she does smile to her mother's voice or touch and the sound of music. She is confined to a wheelchair, a bed or a prone standing device (into which she is strapped) all hours of the day.

To make matters even worse, Caroline's condition has resulted in severe orthopedic problems as she has grown. She was forced to undergo surgery to repair the dislocation of both of her hips. The surgery included tendon releases to her ankles and procedures on her hip muscles. She has severe scoliosis of the spine, which required her to wear a back brace 24 hours per day and undergo an extensive surgery on her spine to fuse it and stabilize it with metal rods.

Caroline will never live a productive life. The failure of her physicians to recognize her increased risk for jaundice and kernicterus, their failure to timely perform necessary diagnostic tests for the condition and their failure to timely treat her have sentenced her to a life of complete dependence. The failures of Caroline's physicians have also sentenced Kathy to a life of caring for a now 11 year old who will, for the rest of her life, have the physical and mental capacities of an infant. Kathy has given up her life to care for her daughter, for whom she had such great plans and dreams. She can no longer work as an executive secretary or in any position outside of the home. She has no social life because she cannot leave Caroline with anyone. She is Caroline's sole caregiver, and that is the only role that Kathy will ever have again.

Kathy's joy in life is seeing the smile and hearing the "laugh" of her daughter when Caroline responds to her mother's voice or touch. It is her only joy. She does not know if Caroline experiences any joy. She doesn't know if Caroline is capable of understanding what joy is. She does know that Caroline experiences pain—she has seen it when Caroline was moved when her hips were dislocated, when she was hospitalized repeatedly for major surgeries on her hips and back. Kathy certainly knows pain; she lives with pain every day—the pain of potential lost, of dreams and hopes dashed, of promise ruined, of normalcy stolen.

Caroline and Kathy's lives have been devastated by medical negligence. Caroline's life as an infant is never ending. Kathy's life caring for an infant is continuous. How is it fair to cap the responsibility of the health care providers who caused this devastation?



Caroline, who is now 11, is blind and profoundly disabled as a result of her doctors' failure to detect and treat high levels of bilirubin in her body in time. Caroline could have led a normal, happy life if her doctors had monitored her as a newborn and treated her with phototherapy or blood transfusions.



Caroline's favorite pony.



Caroline and Arthur.



Caroline at Easter.



Little Irish Lass.



Trick-or-Treat



Caroline believes in Santa Claus.