

## **Baby K**

In October of 1992 an anencephalic baby was born at a hospital in northern Virginia. Anencephaly is a congenital malformation where there is only a brainstem, not the entire brain. It is unusual for such infants to live beyond a few days. The baby's mother and father are not married, and Mrs. K had lost a child the year before in an auto accident.

Baby K was born by C-section, and was intubated after birth. That was kind of anomalous. According to the 1984 guidelines, the infant would certainly count as 'chronically and irreversibly comatose', and any treatment would merely prolong dying, rather than affecting the underlying cause of the infant's condition. Treatment of an infant with anencephaly is certainly well within the parameters of medically 'futile treatment.' That unusual decision may have been prompted by several factors: the mother was anesthetized for the cesarian section, but had asked that the baby be supported; anencephaly had been diagnosed in pre-natal examination, but she had refused the abortion that is usually performed in such circumstances. The staff had hoped—had assumed—that she would agree to non-treatment when she saw the degree of damage to the infant of the malformation and its implications.

She did not agree, and refused a DNR (do not resuscitate) order for Baby K. The distressed staff thought that continued treatment was not advisable. They contacted the ethics committee, who recommended that they continue to work with the mother and (as our guidelines would recommend) seek court approval to override the mother's refusal.

While the hospital was seeking a court order to override the mother's decision, the mother contacted Virginia's state agency for the protection of the disabled, which expressed concern about the hospital's action in light of antidiscrimination legislation and medical neglect legislation. The hospital had tried (and failed) to transfer the child out of their care, but in January they found a nursing home to which she could be transferred, with the understanding that the hospital would treat her if she had breathing problems. She was readmitted three times for breathing problems, had a tracheostomy in April.

In July of 1993 a federal court ruled against the hospital for three reasons: the federal rehabilitation act of 1973, and its successor disability rights legislation, the 1990 Americans with Disability Act; and EMTALA—the Emergency Medical Treatment and Active Labor Act, which regulates admission to emergency rooms for medically indicated treatment. The hospital appealed the decision to the 4<sup>th</sup> circuit court of appeals, which upheld the lower court's decision on the basis of EMTALA (but did not rule on the question of whether anencephaly counted as a 'disability' under the meaning of the act).

The question on which they ruled was: Did congress, in passing EMTALA, provide an exception for anencephalic infants (or anyone else) in respiratory distress? The court ruled that the language was clear: hospitals are required to stabilize the medical condition creating the emergency. "Congress did not..mean for the judiciary to superintend the sensitive decision-making process between family and physicians at the bedside of a helpless and terminally ill patient under the circumstances of this case." In other words, "work it out, folks."

Baby K, against all expectations, lived 2 years and 6 months, and died in the ER of the hospital during her 6<sup>th</sup> admission for respiratory distress when resuscitation failed. It was never decided whether this was the kind of case to which the ADA applied.