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As we move into the second millennium, we cast a backward glance to see where we've been. In bioethics and law, some cases are so well known that their names have become shorthand for a cascade of facts and circumstances. These cases, and the judicial opinions, laws, and regulations they inspired, are frequently referred to by doctors, ethicists, and lawyers.

As part of continuing education for its members, the Institutional Ethics Forum invited Ms Kristi Schrode, J.D., Ph.D., to review and discuss classic cases in pediatrics. In her article, the author provides a brief overview of three such watershed cases involving children. Ms Schrode, holds a doctorate in medical humanities and practices health law and policy in the Washington metropolitan area.

Baby Doe and the "Baby Doe Regulations"

Anyone who spends time in a pediatric ward has heard about the "Baby Doe" regulations. Those regulations were the federal government's response to a cluster of highly publicized cases involving seriously ill newborns. The original Baby Doe was born in Bloomington, Indiana, in April 1982, with a life-threatening tracheo-esophageal fistula and Down's syndrome. The family's doctor had predicted severe retardation and rated his chances of having successful surgery at only 50 percent. Based on this information, Baby Doe's parents refused to consent to corrective esophageal surgery, which could have saved the child's life.

Uncomfortable with this decision, the hospital's medical staff asked a court to appoint a guardian for Baby Doe and to decide whether they should perform surgery over the parents' objections. The trial court concluded that Baby



Doe's parents had chosen a medically reasonable option based on a valid medical opinion. The Indiana Supreme Court refused to hear the case, and Baby Doe died six days after birth, before the case could be appealed to the United States Supreme Court.

There was a great deal of publicity about the Baby Doe case, and Baby Doe's death inspired widespread public discussion of the treatment of seriously ill newborns. In response, the United States Department of Health and Human Services (HHS) issued a "Notice to Providers" in

May 1982, reminding all hospitals receiving federal funds (e.g., Medicare payments) that the 1973 Rehabilitation Act prohibits discriminating against “otherwise qualified handicapped individuals,” including disabled newborns. In 1983, HHS followed up with an “interim rule,” which required hospitals to post signs in maternity and pediatric units encouraging individuals with any knowledge of newborn “mistreatment” to call a federal hotline. Federal investigators (known as “Baby Doe Squads”) would be sent to check out all reports, and hospitals found to be violating the law could lose their federal funding.

The American Academy of Pediatrics (AAP), joined by other medical associations and children’s hospitals, including Children’s National Medical Center (CNMC), successfully challenged the interim Baby Doe regulations in federal court. The court invalidated the rule because HHS had not provided an opportunity for public comment before the rule took effect, but also noted that the system of permitting anonymous tipsters to trigger investigations by “Baby Doe Squads” was not conducive to providing higher quality care for seriously ill newborns.¹

The final Baby Doe regulations, shown below, were published in 1985 to implement the 1984 amendments to the federal Child Abuse Prevention and Treatment Act, which was a compromise between the AAP and right-to-life groups.

Nondiscrimination on the Basis of Handicaps: Procedures & Guidelines Relating to Health Care for Handicapped Infants

1. All such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication.
2. All such disabled infants must be given medically indicated treatment.
3. There are three exceptions to the requirement that all disabled infants must receive treatment, or stated in other terms, three circumstances in which treat-

ment is not considered “medically indicated.”

These circumstances are:

- a. If the infant is chronically and irreversibly comatose.
- b. If the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant.



- c. If the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

4. The physician’s “reasonable medical judgement” concerning the medically indicated treatment must be one that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. It is not to be based on subjective “quality of life” or other abstract concepts.

The final regulations limited sign-posting requirements to staff areas, encouraged hospitals to create “Infant Care Review Committees,” and placed the burden of pursuing violations of the state child protective services—not the HHS. The final Baby Doe regulations attempt to define when withholding “medically indicated” treatment from an infant is medical neglect.

Baby Jane Doe

In October 1983, in the midst of legal wrangling over the Baby Doe Rules, the birth of Baby Jane Doe provided a perfect test case. Baby Jane Doe was born with multiple birth defects, including spina bifida, microcephaly, and

¹HHS’s second attempt to issue Baby Doe Regulations was also thwarted by the federal courts. In 1986, the U.S. Supreme Court held that the Rehabilitation Act does not apply to cases in which parents refuse consent for treatment for their child, and that without evidence of discrimination, HHS did not have authority to require hospitals to post signs and comply with the other requirements of the regulations.

hydrocephalus. Doctors at the University Hospital at Stony Brook, New York, expected Baby Jane Doe to be severely retarded and unable to interact with others. After considering their daughter's prognosis, Baby Jane Doe's parents decided to forgo surgery and provide only food, medication, and nursing care for their baby.

The parents' decision, however, was not the end of the story. An attorney with connections to the National Right to Life Committee intervened to compel the hospital to perform surgery, although he had never met Baby Jane Doe's family and was not otherwise involved in the case. The trial court authorized the surgery, but the appeals court disagreed, finding that Baby Jane Doe's parents had made a reasonable decision about their daughter's care and had her best interests in mind. Ultimately, New York's highest court concluded that it had been wrong for the trial court to allow an unrelated party to intervene in the case, and noted that it was the role of the state child protective services agency to initiate neglect proceedings when they believe that parents are not acting in the child's best interest.

Baby K

One of the most high-profile recent cases in pediatric ethics took place here in the Washington, D.C. area. Baby K was born in October 1992, at Fairfax Hospital in Falls Church, Virginia. Doctors had diagnosed Baby K with anencephaly, a condition in which a baby's brain does not develop above the brain stem. Most babies with anencephaly do not survive very long after birth, and the prevailing standard of medical care is to provide warmth, nutrition, and hydration. Baby K's mother, however, demanded aggressive treatment. Doctors agreed to put Baby K on a ventilator, hoping that her mother would come to accept the diagnosis and realize that mechanical ventilation served no therapeutic or palliative purpose for the child. Instead, Baby K's mother refused to withdraw the ventilator. The hospital ethics committee was unable to resolve the dispute. Baby K was eventually weaned from the ventilator and transferred to a nursing home. Her mother agreed to the transfer on the condition that the hospital would take her back if she had trouble breathing. In fact, Baby K returned to the hospital several times for ventilatory support.



The hospital sought a court order clarifying that neither state nor federal law required it to provide Baby K with "inappropriate" medical treatment (e.g., mechanical ventilation), even if she appeared in the emergency department in respiratory distress. Baby K's father and the child's court-appointed guardian ad litem agreed with the hospital that mechanical ventilation was both ethically and medically inappropriate. In response, Baby K's mother argued that all human life has value and that only God should determine whether her baby should live or die.

Fairfax Hospital lost its case at both the trial court and appellate levels. Both courts based their decisions on the federal Emergency Medical Treatment and Active Labor Act (EMTALA), which requires federally funded hospitals to stabilize patients who arrive with an emergency medical condition. The trial court concluded that the hospital was required to provide ventilatory support to Baby K whenever she presented in the emergency department in respiratory distress, because EMTALA does not provide an exception for anencephalic infants. The judge rejected the hospital's claim that ventilatory support was medically and ethically inappropriate, adding that to hold

otherwise might permit hospitals to turn away accident victims with terminal illnesses such as cancer or AIDS, "on the grounds that they eventually will die anyway." The appeals court agreed with the trial court on the EMTALA issue, concluding that a straightforward interpretation of EMTALA does not permit the hospital to deny Baby K's mother's request for respiratory support in the emergency department. The appeals court noted that the appropriate forum to address this issue is in Congress, which has the power to amend EMTALA to provide exceptions for situations like Baby K's.



Conclusion

A great deal has changed in the pediatric intensive care unit over the last twenty years. Medical advances have enabled doctors to save the lives of many children who would have died only a decade ago and to improve the lives of children born with serious disabilities. Building on the rationales expressed in the courts' opinions in *Baby Doe*, *Baby Jane Doe*, and *Baby K*, new "Baby Does" will lead us to further explore the complex interaction of parental rights, the best interests of the child, professional integrity, and the appropriate use of powerful medical technology.

*To all our new residents and fellows,
"Welcome Aboard!"*

You'll find out more at orientation, but here's a brief word about the Ethics Consult Service. Members of the hospital's multidisciplinary ethics committee rotate monthly on this three-member team. The ECS welcomes your concerns and questions about the consultative process. To reach the physician on-call, press "0" for the page operator, or call the Office of Ethics at Ext. 3201.

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Pass the word to one and all! Beginning with this issue, *Pediatric Ethicscope* will be on the CNMC web page. For our friends and colleagues without internet access, we will continue to place copies near the elevators, outside the payroll window, in the cafeteria, and at the lobby information desk.

Ethics in the Pediatric Literature

End of life care

Sahler OJZ, Frager G, Levetown M, Cohn FG, Lipson MH: Medical education about the end of life care in a pediatric setting: principles, challenges, and opportunities.

Pediatr 2000;105:575-84.

[These recommendations come from a working group of pediatricians and ethicists who convened at a national consensus conference sponsored by the Open Society Institute's *Project Death in America* and the Robert Wood Johnson Foundation.]

Randolph AG, Zollo MB, Egger MJ, Gugatt GH, Nelson RM, Stidham GL: Variability in physician opinion on limiting pediatric life support. *Pediatr* 1999;103 e46.

[Research on how physicians in a pediatric ICU make decisions to withdraw or withhold life support.]

Limits/withdrawal of treatment

Kuczewski MG: Providing comfort or prolonging death for a baby with "dead gut" syndrome. *Cambridge Quarterly of Health Care Ethics* 1999; 8:538-43.

[Ethics committees at work, a case with commentaries by Jacqueline Glover and Carson Strong.]

Goold SD, Williams B, Arnold RM: Conflicts regarding decisions to limit treatment. *JAMA* 2000;283:909-14.

Rhymes JA, McCullough LB, Luchi RJ, Teasdale TA, Wilson N: Withdrawing very low-burden interventions in chronically ill patients. *JAMA* 2000;283:1061-63.

[Two thoughtful reviews and reflections about adult patients but also relevant to children.]

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