

*Should infants born with treatable or manageable handicaps be "allowed" to die? One civil libertarian says no*

# THE AWFUL PRIVACY OF BABY DOE

BY NAT HENTOFF

**E**IGHTEEN MONTHS HAD PASSED SINCE THE INDIANA baby, born with Down's syndrome and a defective digestive system, had been allowed to die of starvation and dehydration. But Linda McCabe, a registered nurse in the special-care nursery of Bloomington Hospital, was still mourning both the infant and her inability to save him.

"At least I wasn't part of the killing," she told me when I asked her to talk about it. "The other nurses in special care and I told the hospital administration we would not help starve that child. So the baby was moved to another part of the hospital, and the parents had to hire private nurses."

Linda McCabe, remembering the evening the orders came to give the baby nothing by mouth and no intravenous feeding, became angry all over again. "Who did they think they were—asking me to do something like that? By the fourth day it got so bad, thinking about that baby just lying there, crying, that some of us nurses started checking in law books to see if we could find some legal arguments to stop the killing of that baby. But as it turned out he only had two more days to live."

I had found Linda McCabe through a Bloomington pediatrician, James Schaffer, who when the baby was born had strongly recommended routine surgery to correct the infant's deformed esophagus, so that he could eat normally. The parents rejected Dr. Schaffer's advice. They did not want a retarded child.

It is impossible to tell so soon after birth whether a child with Down's syndrome will be mildly, moderately, or severely retarded. The coroner wrote later: "The potential for mental function and social integration of this child, as of all infants with Down's syndrome, is unknown."

Nonetheless, the parents had agreed with their obstetrician, Dr. Walter Owens, that a child with Down's syndrome cannot attain what Dr. Owens called "a minimally adequate quality of life." On the baby's last day Dr. Schaffer and two colleagues, despite the wishes of the parents, went, bearing intravenous equipment, to feed the baby. They were too late. The process of dying could not be reversed.

The baby died on April 15, 1982. Two days later *The Evansville [Indiana] Courier* printed a letter from Sherry McDonald: "The night before little Infant Doe died, I called the Indiana Supreme Court and told them I wanted the baby saved. Then my 16-year-old called and said, 'I am a Down's syndrome child and I want the baby boy saved.'"

I had come to Dr. Schaffer and Linda McCabe while trying to learn more about this form of infanticide—the decision by parents and physicians to deny lifesaving medical treatment (and sometimes nourishment) to handicapped babies. I had started looking into the subject because of conversations I'd had, in New York and elsewhere, with nurses and pediatric surgeons who felt that unless more public attention were paid to quiet killings, they would continue and perhaps increase, as if these newborns were still unborn, and therefore subject to the summary judgment of abortion.

One specialist in the treatment of newborns has terminated so many brief lives that, as he told B. D. Colen, the science editor for *Newsday*, he has a recurring dream: "I've died and I'm going to Heaven, and as I go through the gates, I see what looks like this field of gently waving grass. When I look closely, it's babies, slowly undulating back and forth—the babies I've shut off."

A good many of those lives could not have been saved, because the infants were born dying. Even doctors and nurses who are critical of the ways in which irreversible decisions are made in neonatal intensive-care units would not want heroic measures to be taken in these and certain other cases: babies born with only a brainstem, for instance, or with Lesch-Nyhan syndrome, an incurable hereditary disorder that leads to mental retardation, uncontrollable spasms, and self-mutilation.

At issue are lives that could be saved, the lives of infants with such handicaps as Down's syndrome, cerebral palsy, and spina bifida. Spina bifida involves a lesion in the spinal column that can be repaired through surgery, the sooner after birth the better. Without surgery there is considerable likelihood of infection, which can lead to permanent brain damage. Nearly all children with spina bifida also have an accumulation of spinal fluid within the brain. Unless a shunt is inserted to drain the fluid, the pressure on the brain can and often does lead to mental retardation.

As a result of these medical procedures, however, along with knowledgeable follow-up treatment, children with spina bifida can grow up to be bright, productive adults,

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who may need braces in order to walk. Yet death is the prescription some doctors give for newborns with spina bifida. The prediction is that the child will never walk, will be severely retarded, and will suffer progressively worse bladder and bowel problems. In one highly publicized case, that of Baby Jane Doe on Long Island, the physician chosen by the parents added that the child would be in constant pain throughout her dismal life.

The leading medical expert on spina bifida is Dr. David McLone, the chief of neurosurgery at Children's Memorial Hospital, in Chicago. McLone has successfully operated on hundreds of infants with spina bifida, and he and his staff follow the children for several years and perform indicated surgery and other therapy. He asserts that physicians who do not know enough about spina bifida leave infants with that handicap untreated in hospitals throughout the country. In an interview on CBS-TV's *Sunday Morning* last August, McLone said, "Physicians are making decisions not to treat certain numbers of these children on the basis of criteria that are invalid. They are assuming that by examining a newborn child they can predict the quality of life or how independent or how productive that child is going to be, how much stress that child is going to be on the family, how much of a burden on society. They make all of these judgments based on that initial exam, and almost every one of the criteria that they use to make that judgment is invalid."

Invalid or not, as a result of those judgments many infants with spina bifida and other handicaps are allowed to die. It is as if we were already living in that ideal special-care nursery envisioned (in the context of a discussion of quality-of-life issues) by Francis Crick, the 1962 Nobel laureate in medicine and physiology: "No newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and . . . if it fails these tests, it forfeits the right to live."

No one knows exactly how many Baby Does forfeit their right to live each year. No death certificate is going to declare infanticide as the cause of an infant's departure. With regard to babies with Down's syndrome, Dr. Norman Fost, a professor of pediatrics at the University of Wisconsin, noted in the December, 1982, issue of *Archives of Internal Medicine*: "It is common in the United States to withhold routine surgery and medical care from infants with Down's syndrome for the explicit purpose of hastening death." With regard to infants otherwise handicapped, the President's Commission for the Study of Ethical Problems in Medicine declared in its March, 1983, report, "Deciding to Forego Life-Sustaining Treatment": "Decisions to forego therapy are part of everyday life in the neonatal intensive care unit; *with rare exceptions, these choices have been made by parents and physicians without review by courts or any other body*" (emphasis added).

In consideration of the shock and grief of parents, such decisions must be private, the American Medical Association and most physicians insist. The American Civil Liberties Union tacitly agrees. In Baby Doe cases, after the

whistle has been blown by a nurse or a right-to-life organization, not once has an ACLU affiliate spoken for the infant's right to due process and equal protection under the law. Indeed, when the ACLU has become involved, it has fought resolutely for the parents' right to privacy. Baby Doe's own awful privacy, as he or she lies dying, is also thereby protected.

Along with my fellow civil libertarians, most liberals strongly support parents, and only parents, in these situations. It is hard to imagine anyone more powerless than a handicapped baby who has just been given the black spot, but to my knowledge no organization of liberals or civil-rights group has ever said a word about the rights of Baby Does. Nor has any feminist group, even though the civil rights and liberties being violated in these infanticides are not only those of males.

I have discovered, moreover, that most members of these groups do not take kindly to questions on the subject. Some liberals and feminists, for instance, have told me sharply that if I were to look more closely at the kinds of people trying to save those Baby Does, I would understand that such rescue efforts are a way to make women subservient again to those who would tell them what they can and cannot do with their own bodies.

It is true that the most prominent defenders of the Baby Does are such conservative hobgoblins as Ronald Reagan, the right-to-life squadrons, and the Reverend Jerry Falwell. Having picked up bad companions so early in life, the Baby Does indeed bear out the adage that people are judged by the company they keep.

After mighty internal struggles, a few liberals have decided that handicapped infants might, after all, have some constitutional rights independent of their parents' wishes for them. One such heretic, a professor of education with a history of passionate involvement in civil-liberties and civil-rights matters, told me, "For a long time I shut off on this one. If anybody asked, I gave the standard liberal line: 'At a time of such tragedy for the parents, only they have the right to decide. All we can do for them is protect the privacy of their decision.' But then, as part of some research I was doing, I began to talk to handicapped people about Baby Does. I found out how many of them had come close to being killed in the nursery because some doctor thought their 'quality of life' wouldn't be worth a damn. But their parents had rejected that advice, and here were these severely handicapped adults—tough, resilient, leading lives that, however you define that term, were not without 'quality.'"

**M**ANY OF THE DISABLED HAVE SPOKEN FOR BABY Does, in *The Disability Rag* and others of their own publications, and in letters to magazines and newspapers. Indeed, one of the more compelling polemics in the "quality of life" debate was written, a decade ago, by a severely handicapped woman, Sondra Diamond. Her "Letter From a Vegetable," published in *Newsweek*, re-

quires a prologue, because it was one link in a chain of circumstances that began with an article in the October 25, 1973, issue of *The New England Journal of Medicine*.

That article, "Moral and Ethical Dilemmas in the Special-Care Nursery," was the first in an American medical publication in which physicians admitted having withheld treatment from babies until they died. The killings had taken place in the special-care nursery of Yale-New Haven Hospital. (I say "killings" because, as Joseph Fletcher, a theologian who does not object to certain kinds of infanticide, has pointed out, "It is naive and superficial to suppose that because we don't 'do anything positively' to hasten a patient's death we have thereby avoided complicity in his death. Not doing anything is doing something.")

Drs. Raymond S. Duff and A. G. M. Campbell, the physicians who wrote the article, had withheld treatment from forty-three babies over a two-and-a-half-year period. Their report was in no way an act of contrition. They wanted to demonstrate that in certain cases one "management option" in the special-care nursery is death. Those for whom this option was chosen were infants "considered to have little or no hope of achieving meaningful 'humanhood.'" These decisions were made in consultation with the parents, who, Drs. Duff and Campbell pointed out, believed they would be relieved of enormous long-term emotional and financial stress if they chose that particular management option.

Among the infants thus doomed was a baby with Down's syndrome who had a routinely operable intestinal obstruction—a case very much like that of the Bloomington baby. Drs. Duff and Campbell explained in the article that "his parents thought that surgery was wrong for their baby and themselves. He died seven days after birth." He died because he was retarded, although no one had any way of knowing how retarded he would be. (In 1984 the poster of the National Organization on Disability was a photograph of Matthew Starr, of Baltimore, reading the Torah during his bar mitzvah. Matthew has Down's syndrome, but that service was not simplified for him. He also wrote and read the traditional speech given by a boy entering the adult Jewish religious community.)

At the end of their article Duff and Campbell, having discussed the ethical and legal implications of decisions (including ones in which they participated) to let infants die, wrote: "If working out these dilemmas in ways such as those we suggest is in violation of the law, we believe the law should be changed."

An authoritative guide in these particular legal matters is John A. Robertson, a professor of law at the University of Texas and the author of *The Rights of the Critically Ill*. Robertson asserts that an infant born with severe mental and physical disabilities has the same right to be treated as anyone else, new or old. That right, Robertson says, "does not depend on his IQ, physical abilities, or social potential." The only exceptions are "a few very extreme cases in which . . . the burdens of treatment outweigh the bene-

fits," as when the treatment inflicts severe pain and only delays death briefly. Otherwise, even though certain handicapped infants "appear from the perspective of 'normal' people to face a meaningless or greatly limited life," that is no justification "for denying them essential medical treatments."

Accordingly, Robertson says, parents who refuse treatment for infants with such handicaps as Down's syndrome and spina bifida "with the intent and result that they die" can be prosecuted for murder or manslaughter, not to mention child abuse and neglect. Physicians in these cases can also be prosecuted, for homicide, child neglect, and violation of child-abuse reporting laws (the parents should have been reported).

Yet Drs. Duff and Campbell, and the parents who agreed to the denial of treatment for their children, were not charged with any crime. Actually, Robertson says, "while parents of retarded children have been convicted for directly killing them, there has been only one prosecution of parents and doctors for nontreatment of defective newborns." In that case the charges were dismissed, because no one would testify at a preliminary hearing that the parents and doctors had ordered that the Baby Does—Siamese twins joined at the waist—be starved to death.

That prosecutions have been so rare is traceable to a widespread belief that decisions about the welfare of newborn infants should be made only by the parents and physicians. A more proximate factor is the infrequency with which these infant deaths become known outside the nursery. On occasion the refusal of treatment to a handicapped infant does become news—as with the Bloomington baby and, in 1983, with Baby Jane Doe on Long Island. But in neither of these cases were the parents prosecuted.

Very occasionally a court's attention is drawn to a Baby Doe who seems about to die. The hospital, unsure of its legal ground, may initiate the court action lest it be sued later for complicity in the killing of the infant. Or an outsider, learning of the imminent death from a nurse or someone else in the hospital, may try to bring a court action to save the child. No consistent pattern of court decisions has emerged, although treatment has been ordered more often than not in the relatively few cases that have come before a judge.

In one such case an infant was born with only one eye, no ear canals, a deformed esophagus, and almost certain brain damage. He soon developed convulsive seizures of unknown cause. The parents wanted him starved to death, and their doctor agreed. But Justice David Roberts, of the superior court in Cumberland County, Maine, ruled in February, 1974, that "at the moment of live birth, there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself."

The doctor in the case had predicted that should the infant live, he would not have a life worth living. Said Justice Roberts: "The doctor's qualitative evaluation of the

value of the life to be preserved is not legally within the scope of his expertise." The baby died soon after the ruling, but Justice Roberts told me ten years later that he had no regrets about his decision, because the infant had been entitled to his chance to live.

But Justice Roberts would not have known about this Baby Doe if the hospital and, initially, the parents' doctor had not asked for a hearing because they wanted to treat the child (the doctor later changed his mind). No court intervened, however, in any of the forty-three infant deaths described by Drs. Duff and Campbell in their *New England Journal* article. No court knew about any of the cases. Indeed, no one except doctors reading that medical journal might have learned about the killings if *Newsweek* had not picked up the story.

In its coverage of death as a management option at Yale-New Haven Hospital, *Newsweek* used the term *vegetables* to describe some severely handicapped newborns who eventually died. Sondra Diamond wrote a letter to the magazine, and here is some of what she said:

I'll wager my entire root system and as much fertilizer as it would take to fill Yale University that you have never received a letter from a vegetable before this one, but, much as I resent the term, I must confess that I fit the description of a "vegetable" as defined in the article. . . .

Due to severe brain damage incurred at birth, I am unable to dress myself, toilet myself, or write; my secretary is typing this letter. Many thousands of dollars had to be spent on my rehabilitation and education in order for me to reach my present professional status as a Counseling Psychologist. My parents were also told, 35 years ago, that there was "little or no hope of achieving meaningful 'humanhood'" for their daughter [afflicted with cerebral palsy].

Have I reached "humanhood"? Compared with Doctors Duff and Campbell, I believe I have surpassed it!

Instead of changing the law to make it legal to weed out us "vegetables," let us change the laws so that we may receive quality medical care, education, and freedom to live as full and productive lives as our potentials allow.

Four years later, in 1977, Sondra Diamond wrote an afterword in *Human Life Review*. She told of being taken to the hospital with third-degree burns over 60 percent of her body when she was in her early twenties. "The doctors felt that there was no point in treating me because I was disabled anyway, and could not lead a normal life," she reported. "They wanted to let me die. My parents, after a great deal of arguing, convinced the doctors that I was a junior in college and had been leading a normal life. However, they had to bring in pictures of me swimming and playing the piano."

The doctors were still reluctant to treat her, but Sondra Diamond's parents insisted. Once she was again living what she considered a normal life, Diamond observed: "To take the time and effort to expend medical expertise on a person who is physically disabled seems futile to many members of the medical profession. Their handi-

work will come to naught, they think." Even so, she said, "I would not give up one moment of life in which I could have another cup of coffee, another cigarette, or another interaction with someone I love."

Some physicians' prophecies about imperfect babies are shown to be startlingly wrong when the child has a chance to live long enough to confound the prediction. A particularly vivid illustration of auguries turned upside down appeared as part of *Death in the Nursery*, a 1983 series on the Boston television station WNEV-TV. The segment focused on two classmates in a West Haven, Connecticut, elementary school, Jimmy Arria and Kimberly Mekdeci. The boy, born prematurely, had weighed only four and a half pounds at birth, contracted pneumonia a day later, and suffered seizures. The girl was born with spina bifida.

A pediatrician suggested to the parents of both infants that they choose death as the preferred management option. Kimberly Mekdeci's father remembers that doctor saying that his daughter would probably grow up to be a vegetable. The quality of Jimmy Arria's life, the doctor predicted, would be very poor.

Jimmy Arria is a good student; Kim is also bright. According to the parents of both children, the physician who counseled death back in the nursery was Dr. Raymond Duff.

Not all physicians approve of withholding treatment for the parents' and the baby's own good. *The New England Journal of Medicine*, shortly after the Duff-Campbell report had appeared, published a letter from Dr. Joan L. Venes and Dr. Peter R. Huttenlocher, of the Yale University School of Medicine:

As consultants to the newborn special-care unit, we wish to disassociate ourselves from the opinions expressed by [Duff and Campbell]. The "growing tendency to seek early death as a management option" that the authors referred to has been repeatedly called to the attention of those involved and has caused us deep concern. It is troubling to us to hear young pediatric interns ask first, "should we treat?" rather than "how do we treat?"

We are fearful that this feeling of nihilism may not remain restricted to the newborn special-care unit. To suggest that the financial and psychological stresses imposed upon a family with the birth of a handicapped child constitute sufficient justification for such a therapy of nihilism is untenable and allows us to escape what perhaps after all are the real issues—i.e., the obligation of an affluent society to provide financial support and the opportunity for a gainful life to its less fortunate citizens.

**A**FTER MONTHS OF TALKING TO PARENTS, DOCTORS, judges, and a number of the severely handicapped, I thought I had a reasonably clear sense of the scope of deliberate death in the nursery. But then I discovered a new frontier: a death row for infants in Oklahoma.

As Drs. Duff and Campbell had done, the physicians themselves told of the deaths they had caused, and once

again they spoke not in confession but in pride. The article, "Early Management and Decision Making for the Treatment of Myelomeningocele," appeared in the October, 1983, issue of *Pediatrics*, a publication of the American Academy of Pediatrics. Among the authors were Drs. Richard H. Gross, Alan Cox, and Michael Pollay.

Over a five-year period an experiment had been conducted at the University of Oklahoma Health Sciences Center. The subjects of the experiment were newborn infants with spina bifida. Each was evaluated by a team of physicians, nurses, physical and occupational therapists, a social worker, and a psychologist. The team decided, in each case, whether to recommend "active vigorous treatment" or to inform the parents that they did not consider them obligated to have the baby treated; the family could choose "supportive care only." Each infant in the first group was given all medically indicated treatment, including an operation to close the spinal lesion and the implanting of a shunt to drain spinal fluid from the brain. The unfortunate infants relegated to supportive care received no active medical treatment: no surgery, no antibiotics to treat infection, and no routinely administered sedation during the dying process that began inexorably with only supportive care.

Of the twenty-four infants who did not get active, vigorous treatment, none survived. The mean age at death was thirty-seven days. As the babies' physicians wrote in *Pediatrics*, "The 'untreated survivor' has not been a significant problem in our experience."

All but one of the infants who received active, vigorous treatment survived. The exception was killed in an auto accident.

To determine which infants were to be given death tickets, the medical team relied in substantial part on a "quality of life" formula:  $QL = NE \times (H + S)$ .

QL is the quality of life the child is likely to have if he is allowed to live. NE is the child's natural endowment (physical and intellectual). H is the contribution the child can expect from his home and family. S is the probable contribution to that handicapped child from society.

Since under this formula the patient's natural endowment is not the sole determinant of the medical treatment he gets, his chances of being permitted to stay alive can be greatly reduced if his parents are on the lower rungs of poverty. If, moreover, he is poor and has been born during the Reagan Administration—which prefers missiles to funding for the handicapped—the baby has been hit with a double whammy.

The creator of this powerful formula, which has influenced physicians around the country, is Dr. Anthony Shaw, the director of the Department of Pediatric Surgery at the City of Hope National Medical Center, in Duarte, California, and a clinical professor of surgery at the UCLA School of Medicine. He is also the chairman of the Ethics Committee of the American Pediatric Surgical Association. When I charged Dr. Shaw, during a television debate, with having created a means test for deciding which infants

shall continue to live, he said he had intended no such thing. I asked him how else one could read his formula, and he said that its purpose was to help the parents. And, of course, the baby.

The last two elements of the formula, plainly, have nothing to do with medical judgments. Yet Martin Gerry, a civil-rights lawyer who was the director of the Office for Civil Rights of the Department of Health, Education and Welfare from 1975 to 1977, and who investigated the Oklahoma experiment, found that the parents of the infants involved "were told by representatives of the [medical] team that the proposed treatment/non-treatment alternative represented a medical judgment made by the team. The quality-of-life formula used was neither discussed with nor revealed to the parents."

An appalled reader of the article in *Pediatrics* was Dr. John M. Freeman, of the Birth Defects Treatment Center at Johns Hopkins Hospital, in Baltimore. Writing to *Pediatrics*, Freeman observed that while the Oklahoma medical team did prove that it "can get the infants to die quickly," such skill hardly qualifies as "the best available alternative" for the management of babies with spina bifida. Dr. Freeman added that the twenty-four infants who died "might also have done well and might have . . . walked with assistive devices, gone to regular school, been of normal intelligence, and achieved bowel and bladder control."

Should anyone be charged with criminal responsibility for their deaths? "The facts, just as written by the doctors themselves in the article, clearly demonstrate violation of both state and federal law," Martin Gerry says. "I think there are clearly violations of state child-abuse laws; there are violations of state criminal laws. I think what you have here is a conspiracy to commit murder." So far, however, no prosecutors have been interested in going after indictments. The Reagan Administration says it is unsure that it has sufficient legal basis—given the laws in force at the time of the Oklahoma experiment—for moving against doctors who withheld treatment.

Two years ago, however, after the death by starvation of the baby with Down's syndrome in Bloomington, Indiana, President Reagan angrily ordered the secretary of the Department of Health and Human Services to apply Section 504 of the Rehabilitation Act of 1973 to handicapped infants. Section 504 says that under any program receiving federal assistance a handicapped person cannot be discriminated against because he or she is handicapped. Accordingly, handicapped infants must—like all other infants in the nursery—be fed and given appropriate medical treatment.

Regulations came down from Washington to enforce the application of 504 to handicapped babies. A hotline was set up so that anyone hearing that treatment or food was being denied a Baby Doe could report the details to federal investigators. And the Justice Department claimed that because of Section 504 it had the authority to review a Baby Doe's medical records in order to determine whether the baby was being discriminated against.

SO IT WAS THAT THE JUSTICE DEPARTMENT DEMANDED the records of Baby Jane Doe, the Long Island child born with spina bifida whose parents, acting on the advice of their doctors, had refused operations to close the spine and to insert a shunt in order to drain the fluid pressing on her brain. (Months later a shunt was implanted.)

The privacy of Baby Jane Doe was protected against the federal government by the attorney general of the State of New York, the New York Civil Liberties Union, the American Hospital Association, the American Academy of Pediatrics, and other medical groups. Supporting the Administration's position were the American Coalition of Citizens with Disabilities, the Association for Retarded Citizens, the Association for the Severely Handicapped, the Disability Rights Education and Defense Fund, Disabled in Action of Metropolitan New York, and the Disability Rights Union. They said they were on the side of Baby Jane Doe.

The federal government lost all the way, up to and including the United States Court of Appeals for the Second Circuit, where, on February 23, 1984, a panel decided 2 to 1 that if Congress meant Section 504 of the 1973 Rehabilitation Act to apply to Baby Does, it ought to say so loud and clear. Until then the privacy of the parents and of the infant must not be violated.

In a strong dissent, overlooked by much of the press, Judge Ralph Winter wrote that the question wasn't even arguable. He drew an analogy to race. "A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life-threatening digestive problem because an infant has Down's syndrome is not a *bona fide* medical judgment." Both decisions are acts of discrimination. Buttressing the logic of this analysis, Winter added, was the fact that Section 504 of the Rehabilitation Act of 1973 had been patterned after, and is almost identical to, the anti-discrimination language of Section 601 of the Civil Rights Act of 1964.

No major newspapers that I know of published editorials lauding Judge Winter's dissent. Practically all of the nation's leading and lesser newspapers had claimed throughout the odyssey of Baby Jane Doe that the infant and her parents were being persecuted by a grossly intrusive and insensitive federal government.

Baby Jane Doe had been saved from Big Brother. "The federal government," said Richard Rifkin, a spokesman for the attorney general of the State of New York, "is now barred from conducting any investigation of medical decisions regarding defective newborns."

Liberals and civil libertarians cheered. This had been one of their few victories over Ronald Reagan.

Signs persisted, however, that Congress might come to the aid of Baby Does. On February 2, 1984, the House debated with much passion a bill to extend the Child Abuse Prevention and Treatment Act. The amendments to one section broadened the definition of child abuse to include

the denial of medical treatment or nutrition to infants born with life-threatening conditions. The section also mandated that each state, to keep getting funds for child-abuse programs, would have to put in place a reporting system that could be alerted whenever a handicapped infant was being abused by denial of treatment or food.

Liberals led the debate against those provisions on the House floor, and conservatives, by and large, supported the measure. Particularly eloquent was Henry Hyde, an unabashed Tory, whose history of implacable opposition to abortion reinforced the view of many liberals, in and out of the House, that all of this compassion for Baby Does was actually propaganda to gain sympathy for the unborn.

"The fact is," Hyde said during the debate, "that . . . many children . . . are permitted to die because minimal routine medical care is withheld from them. And the parents who have the emotional trauma of being confronted with this horrendous decision, and seeing ahead a bleak prospect, may well not be, in that time and at that place, the best people to decide. . . . I suggest that a question of life or death for a born person ought to belong to nobody, whether they are parents or not. The Constitution ought to protect that child. . . . Because they are handicapped, they are not to be treated differently than if they were women or Hispanics or American Indians or black. [Their handicap] is a mental condition or a physical condition; but by God, they are human, and nobody has the right to kill them by passive starvation of anything else."

On the key vote concerning this section of the bill Congresswoman Geraldine Ferraro joined other renowned liberals in the House in voting against protections for handicapped babies, though most, to be sure, said they were supporting the right of parents to make life-or-death decisions about their infants and opposing government interference in that process. Among the others in opposition were such normally fierce defenders of the powerless as Peter Rodino, Henry Waxman, Don Edwards, Barney Frank, John Conyers, Thomas Downey, Charles Rangel, Robert Kastenmeier, Gerry Studds, George Crockett, and Barbara Mikulski.

The vote on expanding the definition of child abuse to include the neglect of handicapped infants was 231 to 182 in favor. Not until July, however, did the Senate pass a bill protecting the lives of Baby Does. An unusually ecumenical team of senators sponsored the bill: Orrin Hatch, Alan Cranston, Christopher Dodd, Jeremiah Denton, Don Nickles, and Nancy Kassebaum. Edward M. Kennedy was involved until nearly the end.

Handling the day-to-day maneuvering were members of the staffs of various senators. They were continually fearful that the fractious coalition of medical, right-to-life, and disability-rights organizations that had to agree on the language of the bill would fall apart. Yet at the end the AMA was the only medical group to walk out. Its representative had kept insisting on the need to allow physicians to make "quality of life" decisions as to whether an infant should

live or die. Staying behind and signing the agreement were, among other medical organizations, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American College of Physicians, and the American Nurses Association.

As finally passed, the Senate bill (which, with a few modifications, was accepted by the House in conference) redefines child abuse and neglect, for purposes of this federal statute, to include "the withholding of medically indicated treatment from disabled infants with life-threatening conditions." No heroic measures are required, however, if treatment would merely prolong dying and would be "virtually futile in terms of the survival of the infant," or if the baby "is chronically and irreversibly comatose."

Under this Child Abuse Prevention and Treatment Act each state, in order to get federal child abuse and neglect grants, is required to create a system for reporting to state child-protection agencies cases in which infants are being denied treatment. As a last resort these agencies have the authority to "initiate any legal remedies" needed to prevent such a child from being killed. In effect, this means that Baby Does have rights independent of the rights of their parents. If they are not born dying or irreversibly comatose, handicapped infants, as persons under the Constitution, are entitled by federal statute to due process and equal protection under the law.

Meanwhile, the American Medical Association is likely to test all this in court, having already indicated its preferred approach to the Baby Doe question. On June 20 delegates to the AMA's 133rd annual convention, in Chicago, voted to support the concept of "local option" for Baby Does. That is, they wish communities and hospitals to have the legal right to set their own life-or-death standards for handicapped infants. Baby Does to come are not out of danger. Parents as well as doctors will be trying to get the new law struck down.

One of the first things I did when the bill passed was to send the news to a woman in Mount Airy, Maryland, who has been much dismayed at the infanticides in the nurseries in her county. She told me of going to a hospital seminar on the subject a couple of years ago and listening to the head of a neonatal nursery staff complain that it was awfully hard on her nurses when a baby deprived of treatment took fifteen days to die. Other infants, she felt the lecturer had implied, were more accommodating.


This woman in Mount Airy had written to me last summer: "As a social studies teacher of ancient civilizations, I conducted classroom discussions covering the topic 'Ideals of Sparta vs. Ideals of Athens.' It was always . . . a shock for my students to learn that the Spartans, who valued 'body' over 'mind,' could be as callous and cruel as to leave their deformed newborns on the rocky hillsides to die.

"In this matter, it would seem, we have not come very far. What shall be written of us in years hence? That we merely brought this barbaric practice indoors?" □

# SUNDAY

THE CHICAGO TRIBUNE MAGAZINE

FEBRUARY 10, 1985



## THE LONELIEST CHOICE

One couple's  
decision to let  
their newborn die

# The death of Baby Doe

How a decision in a small Midwestern hospital touched off a nationwide debate.

Article by Jeff Lyon

**T**he town of Bloomington lies just beyond that point in Indiana where the land turns with improbable suddenness from the flat monotony of the north to the rolling beauty of the south. All at once, the rivers seem to quicken, and you are in hills thick with elegant oak and hickory trees. It is shy country, green and dark, where the bridges wear head shawls and lovely ravines drop away and out of sight. Everywhere is the gentle warning that the road is guest here, now and always.

Bloomington itself has lost some charm in recent years. The town's most picturesque features—a rugged 19th-Century courthouse and the ivy-clad campus of Indiana University—coexist cheek by jowl with shopping plazas, auto-parts stores, and junk-food emporiums designed to woo the student trade. But if some of its scenery has changed, the essence of the town has not. It remains as peaceful and serene as the encircling countryside, a tightly knit, homespun community that is both protective of traditional values and tolerant of the liberal university population it hosts.

In the spring of 1982, however, this tranquility was disrupted by a tragic and controversial episode. A Bloomington couple allowed its infant son to die of a treatable birth defect. The child, who succumbed while surrounded by willing rescuers, has become known to the world as Baby Doe, his identity sealed by the courts to protect his parents. We will continue to respect their privacy by not naming them in this story.

Though Baby Doe's whole existence was compressed into a matter of days, it left more of a mark on the nation than lives of far greater duration. The impact of his death was felt in the White House and in virtually every hospital nursery in the United States, and it triggered a nationwide debate that shows no signs of fading.

*Jeff Lyon is a Tribune feature writer. This story is excerpted from his book "Playing God in the Nursery," an examination of the ethical and social implications of decisions not to treat impaired newborns, to be published later this month by W.W. Norton & Co.*

But the most immediate effect of the Baby Doe case was on the people of the town, who were painfully divided into two camps by the issue. The parents found themselves supported by some of their neighbors and reviled by others. The child's doctors nearly came to blows over him, and one even contemplated kidnapping the boy on the night of his death. Some of his nurses subsequently required psychiatric counseling to overcome their sense of guilt. And today, almost three years later, the community's scars have not completely healed.

Good Friday, April 9, 1982. The afternoon light was dying as Walter Owens, a large, slightly rumped man with a graying goatee, hurried into the rear entrance of Bloomington Hospital, where one of his patients had just gone into labor.

As Owens strode through the antiseptic halls on his way to the maternity ward, he had no way of knowing what an emotional hurricane would be unleashed during the next few hours. His thoughts were confined to the clinical details of the birth that lay ahead. The mother, a petite woman with closely cropped hair, was 31 years old. Her pregnancy had proceeded quite normally, and she had previously given birth to two healthy children. There was no reason to expect anything other than a routine delivery.

Owens was pleased to be involved in the case. He was genuinely fond of the parents, a pair of former schoolteachers who had given up the classroom several years earlier—she to raise her children, he to become an executive with a Bloomington firm. Owens found them to be pleasant, conscientious people with a straightforward manner. They had been married for seven years and were both looking forward to the birth of their third child. The father, a dark, heavyset man of 34, seemed to be brimming with delight. He had taken Lamaze natural-child-birth classes with his wife and was eager to coach her through the delivery.

Scanning the medical chart, Owens noted only one indication that something might be wrong. It had manifested itself when the woman's amniotic sac burst, 45 minutes after her admission to the hospital. She began to pass amniotic fluid of an abnormal, greenish color. This "staining" of the fluid signifies that the fetus is giving off a waste product known as meconium, which is sometimes, but not always, an SOS, suggesting that it may not be getting enough oxygen.

In the absence of any other warning signals, however, Owens was not overly concerned. At about 7:30 p.m., with labor progressing nicely, he made his way to the doctors' lounge and slipped into his hospital garb. Then, after carefully scrubbing up for the birth, he joined the parents in the delivery room, the smallest of three such units on the hospital's second floor. The only other person in the room as Owens began to deliver the baby was a nurse, Dana Watters.

Over the next 40 minutes, everything went smoothly. Owens could not have asked for a more uncomplicated birth.

The time of delivery was logged at 8:19 p.m., and it was at that instant—as he placed the infant on its mother's abdomen—that Owens saw he had a catastrophe on his hands.

The baby was as limp as a rag doll. Blue from lack of oxygen, it lay scarcely breathing, its small heart pumping raggedly, like an engine that won't turn over. Its initial Apgar score, a rating system used by doctors to evaluate a newborn's physical state, was 2 out of a possible 10.

But Owens observed something else in the small, flaccid body that lay before him, something that made his heart sink. He saw the telltale signs of Down's syndrome, the mysterious realignment of the 21st chromosome that consigns a child to a life of mental retardation.

The mother, too, must have seen something in the child's face. "You look beautiful," she crooned, stroking the infant on her belly. "You look different from my other two, but I love you anyway."

**B**ut there was no time to ponder the situation. The child needed help to breathe. Owens tried flicking his fingers against its tiny chest to stimulate respiration, but it responded weakly. He nodded at Mrs. Watters, who whisked the baby to a nearby radiant warming table, where she began feeding him oxygen via a hose from the wall. At last the infant began to breathe normally, and his color brightened. Mrs. Watters gave a thumbs-up signal to Owens, who was delivering the placenta. The veteran obstetrician relaxed somewhat.

Mrs. Watters then took up what is known as a DeLee trap and threaded it into the child's eso-



Illustration by Brad Holland

phagus to suck amniotic fluid from the stomach. But as she slid the slender tubing down the throat, she felt it suddenly stop. She tried again.

"I can't pass the catheter, Dr. Owens," she murmured anxiously.

The two of them peered at each other over their masks. They both knew what that meant.

"Esophageal atresia," thought Owens grimly.

An esophageal atresia is a condition in which the baby's esophagus ends in a blind pouch, then may resume farther down. The net effect is that of a washed-out bridge. No food can reach the stomach.

Very often the defect occurs in tandem with a complication known as a tracheoesophageal fistula, in which the lower, or stomach, end of the interrupted esophagus may hook directly into the windpipe. The child will have trouble breathing, being unable to rid itself of mucus, and eventually its lungs will be "digested" by its own stomach juices backing up. Owens suspected the child had a fistula as well.

The mother's face seemed to cloud over as she waited for Owens to stop examining the baby. He was taking forever, much longer than he should. "What's wrong?" she asked, alarmed.

Mrs. Watters bit her lip. "We seem to be having some difficulty getting the tube down into his stomach," she replied.

The father, his nondescript surgical outfit concealing the apprehensive man inside, kept his wide eyes focused on the doctor.

"Is . . . he going to be all right?" he stammered.

"We're going to have to see," Owens said solemnly. Believing a second opinion to be in order, he asked the father who their family doctor was. Their general practitioner was Dr. Paul Wenzler, the man replied, but where their children were concerned, Dr. Wenzler consulted with Dr. James Schaffer, a prominent Bloomington pediatrician.

Owens told Mrs. Watters to get Schaffer on the phone immediately. By chance, Schaffer was already in the hospital making rounds. He agreed to examine the baby in the special-care nursery. Mrs. Watters bundled up the infant and set off on the trip down the hall. As she rushed out of the room, the husband looked imploringly from her to the face of his son. Then he buried his head in his hands.

**J**ames Schaffer studied the infant. There was little doubt that it had Down's syndrome.

Next, he, too, tried to pass a catheter down the baby's esophagus. Just as before, it would not go down. Schaffer was not surprised. Down's syndrome is frequently accompanied by other malformations. He ran his expert hands along the child's limp body, and soon he noticed something else amiss. There was a weak pulse in the child's leg, a symptom of a constricted main artery. Sure enough, when a chest X-ray came back, it seemed to show that the heart was abnormally enlarged.

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# Baby Doe

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While Schaffer was examining the infant, Mrs. Watters returned to the delivery room. She found Dr. Owens explaining to the baby's mother and father that their son appeared to have serious birth defects. Both parents were crying. The discussion lasted only a few moments before it was time to wheel the exhausted mother to the postpartum recovery room. As is her custom when a child is born with defects, Mrs. Watters assigned herself to stay with the couple for the rest of the evening. She feels people should not be handed off to new nurses at such an emotionally delicate time.

Moments after the couple left the delivery room, Schaffer appeared and began to confer with Owens. Joining them was Wenzler, who had just arrived at the hospital. Their discussion was brief. The facts of the child's handicaps seemed clear enough. All that remained was to outline for the parents what the treatment options were.

The three doctors filed into the recovery area, where the mother lay in silence. Her husband was pacing the floor. As gently as possible, the physicians began to explain the prognosis for the couple's newborn son.

Schaffer spoke first. In his opinion, the child needed an immediate transfer to James Whitcomb Riley Children's Hospital in Indianapolis. Riley was equipped to surgically repair the boy's esophagus and trachea; Bloomington Hospital was not. Without an operation, Schaffer explained, the child would die.

Dr. Wenzler concurred. Without the operation, the boy would not be able to eat or drink. Anything he took by mouth would cause him to suffocate.

Then it was Owens' turn to speak. "It was right at that moment," Schaffer later recalled, "that everything went to hell."

Owens could simply have joined Wenzler in seconding Schaffer's recommendation. Had he done so, a chapter in American moral politics might never have been written. But he saw things a different way. The operation, he told the parents, could indeed save the child's life. But it was a rigorous procedure, generally accompanied by a significant amount of pain, and it frequently required follow-up surgery over several years. Above all, he reminded them, it could do nothing about the Down's syndrome. The child would still be retarded for the rest of his life.

"However," he informed the parents, "you do have an alternative."

What they could do, he explained, trying to choose his words carefully, was in effect do nothing: Simply refuse consent for the surgery, in which case the baby would die of pneumonia in a few days as the digestive juices attacked his lungs.

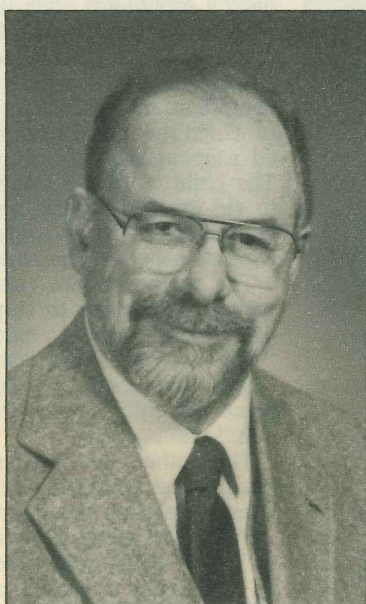
Having said his piece, Owens fell silent.

Why would a doctor whose entire career had been

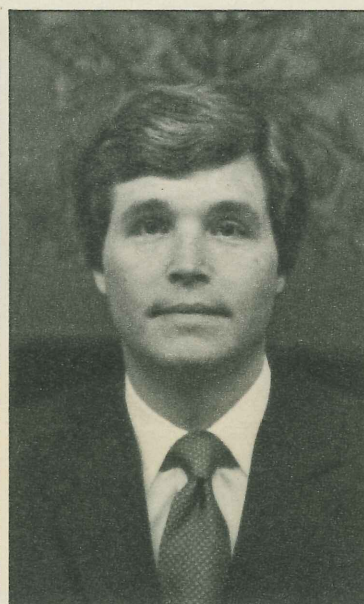
devoted to bringing babies into the world now raise the option of letting one die? Owens later ascribed his behavior to an experience he'd had years before. His nephew's wife had given birth to a malformed baby, among whose defects was one requiring major surgery. It was performed at once, at the pediatrician's recommendation. When numerous bouts of pneumonia subsequently afflicted the infant, the same pediatrician vigorously treated them.

"But the child has never been normal," Owens explained. "It learned to walk at the age of four, and it has never learned to talk. It is, at times, aggressive and destructive. My nephew and his wife are very strong people and have handled it. But they've had no more children. She has devoted her whole life to caring for this child."

"Obviously, this has colored my thinking on the survival of such children. I believe there are things that are worse than having [such] a child die. And one of them is that it might live."



Dr. Walter Owens:  
"You do have  
an alternative."



Judge John Baker:  
"I think Indiana  
law is clear."



Dr. James Schaffer:  
"Everything went  
to hell."

Photos by Larry Crewell/Bloomington Herald-Telephone

The pediatrician who had recommended surgery for Owens' grandniece and who had treated her pneumonias so vigorously was Dr. James Schaffer.

It was 9:30 in the evening. The doctors suggested the parents take some time to weigh their options. The emergency was not so critical that they had to decide on the spot. The couple nodded.

In the interim the three doctors sat drinking coffee at the nurses' station. A chill had descended upon them since Owens had suggested nontreatment. They did not speak.

At almost the stroke of 10 p.m. the father appeared in the doorway. "We've reached a decision," he announced softly. For a moment he seemed to have trouble with the words. But at last, with a glance at Owens, he said, "We have decided that we don't want the baby treated."

Schaffer looked shocked. Immediately, he began to remonstrate with the father. Didn't they understand that the baby would die without treatment? Yes, they did understand, the man said. But they were nevertheless withholding consent.

With his colleagues looking dumbfounded, Owens leaped up to congratulate the father. "You've made a wise and courageous choice," he told the man. "Here's how I look at it. If you let the baby die, you're going to grieve a little while. But if you go

ahead with this surgery, you're going to grieve for the rest of your lives."

Schaffer stalked out of the room. A few minutes later, when Owens entered the special-care nursery to check on the baby, he found Schaffer speaking by telephone with the chief physician on duty at Riley Hospital's neonatal intensive care unit.

"I want you to talk to this man," Schaffer told Owens tersely.

Owens took the receiver. Right away, as Owens remembers it, the doctor on the phone became threatening. This was infanticide, the physician said heatedly, and there were laws against such a thing. "There's going to be a court order to take control of this child," he warned Owens. "You can be sure of it."

Saturday, April 10, was the lull before the storm.

Owens, in consultation with the parents, drew up the infant's treatment order. The order stipulated the following: [1] Hospital personnel might feed the child orally if they wished, but they should be advised that it was likely to result in aspiration and death; [2] Intravenous feedings were positively forbidden; and [3] The child should be kept as comfortable as possible and given sedation as needed.

The treatment order was taped to the side of the baby's Isolette. That accomplished, the couple had a second unhappy piece of business to attend to: talking to an attorney. There had been threats of legal action on the night of the birth, and now the hospital management was acting strangely. An administrator had begged them to take the child home, and when they had refused, he had asked them to sign a release absolving the hospital of responsibility for the baby's death.

The father's boss suggested a lawyer named Andrew Mallor. A few phone calls were made, and Mallor agreed to take the case.

One can hardly blame the hospital administrators for being nervous. A child with a treatable medical condition was being allowed to die in their special-care nursery. Aside from humanitarian questions, there was the issue of legal culpability. If the baby died on the hospital's grounds, could the institution be held criminally liable?

On Saturday night the hospital's attorney, Len Bunger, came up with what appeared to be the perfect solution—a judicial hearing. A judge could order the parents to send the child to Riley. And a judge could take custody of the day-old infant away from them if they refused. At the very least, Bunger reasoned, it would take the responsibility off the hospital's shoulders.

He set about arranging a hearing. Bunger's first call was to Circuit Court Judge James Dixon, who would normally hear such cases, but Dixon was unavailable. The next name on the list was that of Judge John Baker, of the superior court.

Baker, 35, was at home coloring Easter eggs with his three young children when Bunger's phone call came. Bunger apologized for the late hour—nearly

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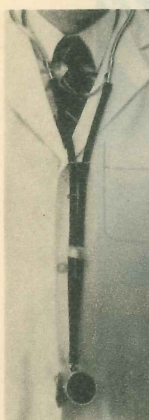


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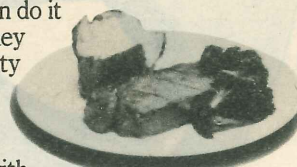
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## Baby Doe

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10 p.m.—but stressed that it was a matter of extreme urgency. Baker listened as the attorney explained the details of the case. Then he agreed to call an immediate hearing.

Attorney Andrew Mallor was just walking in his front door when the telephone rang. He had spent the evening attending a ballet recital with his daughter. Picking up the receiver, he was surprised to hear the angry voice of the baby's father.

"We've just been informed," the father said, "that they're going to hold a hearing at the hospital in 10 minutes."

**T**he site of the hearing was a storage room on the hospital's sixth floor. With the rest of the medical complex undergoing extensive remodeling, the room had been pressed into service for conferences. Ordinarily, the sixth floor is a utility area, which, on a late Saturday night, imbued it with an eerie quality. The elevator doesn't even go that high; one has to get off at five and walk up a flight of stairs.

Baker gavelled the hearing to order at 10:30 p.m. Actually, *gavelled* is the wrong word. Baker had no judicial accoutrements whatsoever—neither gavel, robes, law books, nor legal briefs. As he began to consider whether the child lying four floors below should be allowed to live or die, his only tools were a note pad and an open mind.

The questions to be resolved were of a significance strangely out of proportion to the surroundings—the makeshift conference room with its ring of chairs. At issue was nothing less than whether parents ever have the right to refuse life-saving treatment for their children and whether a life of handicap is so abysmal as to warrant its termination at birth.

Only rarely in American jurisprudence had such questions been raised. On the few occasions on which they had, the courts had almost invariably ruled against the parents and in favor of life. But in those instances the doctors had always been lined up *against* the parents.

In Bloomington, however, it was a different matter. There existed a strong—one might say vehement—division of clinical opinion as to what the best course of treatment was. An experienced and much-esteemed physician, Dr. Walter Owens, was willing to go on record with the medical judgment that the child was better off dead.

Even so, nobody in the room seriously expected Baker to deviate from the usual legal finding that a handicapped child, like any other citizen of the United States, is protected by the Constitution's guarantees of life, liberty, and property, and that no one—be it court, doctor, or parent—could abrogate those guarantees.

Walter Owens was the first witness. He ran through the events of the night before and explained that when Schaffer and Wenzler had begun to propose all-out

surgical intervention, it had set off something inside him. Believing it wrong to allow the parents just that one option, he had insisted on "giving the parents a choice." Owens said he felt certain the boy's level of mental retardation would be so severe that he would never enjoy even a "minimally adequate quality of life."

The testimony began to swing around the room. First Schaffer, then Wenzler, then James Laughlin, another pediatrician, declared that the only "acceptable" course of medical treatment was to send the infant to Indianapolis, where, as one of them put it, he could receive a "full-court press."

Laughlin disagreed with Owens about the prognosis for a Down's-syndrome child. He said he had personal knowledge from his own practice of three Down's children who enjoyed a "reasonable" quality of life.

Judge Baker's pen made scribbling noises as he took notes on his legal pad. Then he called on the father.

John Doe, as the man was referred to in the court record, tried to explain the couple's position. For seven years, he told Baker, he had been a public-school teacher. In that time, he'd had occasion to work closely with handicapped children, including children with Down's syndrome. These experiences had left him with the opinion that Down's children never lead very good lives, an opinion that his wife shared. Faced with a Down's child of their own, they had decided it would be wrong to subject him to a life of such an inferior kind.

There were also their two other children to consider. A severely handicapped child would place a tremendous burden on the family as a whole. For all of these reasons, the father said, he and his wife had chosen to allow the baby to die.

It was almost 1 a.m. when the testimony ended. All eyes fell on the judge. Baker announced that he was going to leave the room for a while to consider his decision. It was no more than 30 minutes before he returned.

Baker cleared his throat and began to read. Since there were two divergent medical opinions, he said, it was his conviction that the Does had every right to select one of the two. It was not for the court to decide which they should choose. The child would be permitted to die.

Owens patted Mr. Doe on the shoulder. The father's face seemed to melt with relief. Schaffer rose slowly from his chair. He was utterly astonished.

**E**aster Sunday, April 11. The special-care nurses revolted, threatening to walk off the job if the baby wasn't removed from the nursery. His presence among women whose every professional and human instinct was to nurture him was like an open wound.

Linda McCabe, head nurse in the unit, vividly recalls coming to work that weekend and seeing the child lying in its incubator with a "Do not feed" order taped to the side. "I felt like they had a

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## Baby Doe

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lot of gall asking me to do that. I thought, 'Over my dead body.'"

To quell the uprising, the hospital hastily transferred the child to a private room on the fourth floor. The Does found themselves forced to hire private nurses who could watch the child around the clock and comfort him. But they were not allowed, under hospital rules, to give him drugs. Only the fourth-floor nurses could administer the morphine shots and phenobarbital prescribed to keep the baby calm and pain-free as his life slipped away. One of them, Teleatha McIntosh, says she found the task emotionally devastating. "Without a doubt, it was the most inhumane thing I've ever been involved in," she recalls. "I had all this guilt, just standing by, giving him injections, and doing nothing for him." But even nurses who raged at the parents for their decision had to admit they were attentive and loving to their child, frequently visiting the bedside and cradling him in their arms.

**E**arly on Monday morning the Does, who are Catholic, had the child baptized. The sacrament was performed by their parish priest, who had indicated support for their decision. They named the child Walter, after Dr. Walter Owens.

By this time, pressure on Judge Baker was beginning to build. Local right-to-life organizers were bitterly assailing him, particularly for his failure to appoint a guardian *ad litem* [a legal advocate] to speak on behalf of the child at Saturday night's hearing. To answer such criticism, the judge appointed the Monroe County Department of Public Welfare guardian *ad litem* and asked its Child Protection Committee to review his decision.

The committee hearing was held on Monday night in the same hospital storage room. After 45 minutes of deliberating, the committee announced that it found no reason to disagree with Judge Baker's ruling.

Walking wearily out of the building, the father turned to Mallor, wanting to know whether the ordeal was finally over.

"Yeah, that's it," Mallor replied confidently. "I can't imagine anything more."

The next morning, however, in the aging courthouse in the center of town, events were taking place that would prove him wrong. The county's young prosecutor, Barry Brown, and his deputy, Lawrence Brodeur, were offended by the progress of the case. To Brodeur, it seemed to create a frightening new precedent permitting parents, if they didn't like their child, simply to end its life.

The two of them brooded over how they could best overturn Baker's judgment. They decided to have the child declared neglected under Indiana's Child in Need of Services [CHINS] statute. Joining them in this petition was Philip Hill, a local attorney.

For the third time that week, a hearing

In **SUNDAY**:  
A weekly look at Chicago's colorful past  
in The Way We Were

was held on virtually a moment's notice. Stating that the Does were following "a medically recommended course of treatment for their child," Acting Judge C. Thomas Spencer ruled that there was no violation of the CHINS statute. "The Court finds that the state has failed to show that this child's physical or mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parents to supply the child with necessary food and medical care."

Even as Spencer sat reading his decision at 8 p.m. on Tuesday night, the infant lay in his incubator, dying. His body weight had dropped from lack of nourishment. He was crying from hunger, and his lips were parched from dehydration. His ribs were sticking out, the result of respiratory strain. That afternoon, when the stomach acid started corroding his lungs, he had begun to spit blood.

The nurses did what they could. They turned him over, gave him back rubs, and put glycerin-soaked swabs into his mouth to ease the dryness. They also diligently suctioned the blood from his throat. Despite their best efforts, however, it was clear he had less than 48 hours to live.

Again the father asked Andrew Mallor whether Spencer's ruling was the end. He and his wife were walking an emotional tightrope.

"Yes, that's finally it," said Mallor.

Instead, there began a series of frantic, last-ditch efforts by the opposing side. At 11 o'clock that night attorney Hill sought and failed to get a temporary restraining order from Judge Baker authorizing intravenous feedings.

The next day, a National Right-to-Life Association lawyer named James Bopp entered a petition on behalf of an Evansville couple who said they were eager to adopt the child. Appearing in court for the parents, Mallor angrily replied that the Does were withholding surgery from the child not because they wished to be free of it but because they thought it inhumane to make it go through life with Down's syndrome and other defects. To grant an adoption petition would be tantamount to saying they were abandoning the child.

The petition was denied.

Brodeur and Hill, meanwhile, carried their appeal to the Indiana Supreme Court. Without explanation, the Supreme Court turned them down, voting three to one to do so.

**T**hursday began as Lawrence Brodeur was about to play his final card. Accompanied by a constitutional expert from Indiana University, Brodeur booked a flight to Washington, D.C., where he planned to file an emergency appeal with the U.S. Supreme Court.

But time was running out for Baby Doe, as the press had christened him. He had begun to hemorrhage freely, the blood oozing from his nose and mouth. Three times Thursday afternoon and evening he had stopped breathing, only to fight his way back.

Nurse Bonnie Stuart, who was working the 3-to-11 shift that day, recalls seeing Mrs. Doe looking troubled. "I never saw the lady cry, but she looked like she hadn't slept

continued on page 18

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## Baby Doe

continued from page 17

much. She'd ask me if I thought it would be much longer, like she was hoping it would be over soon. I never replied. It was not a friendly conversation. I wish I'd never seen the woman."

Stuart says the mother left early in the shift, which particularly upsets her. "I feel the parents could have been there for the death," she says bitterly. "I'm angry at them for involving me and then backing out, making me take care of him."

As the hours continued to pass that evening, Dr. Schaffer came in a number of times to look at the infant. He would shake his head and walk out.

It was after dinner that Owens began receiving what he says were "peculiar" telephone calls from the hospital, asking him why he had ordered no food for the baby. Suspicious that he was somehow being "set up," he immediately drove to the hospital, where he posted himself next to the child's incubator.

Within a few minutes there occurred one of the most bizarre episodes in the history of American medicine, an episode that saw one doctor guard a dying baby from another doctor who was threatening to try and save its life.

According to Owens' version of events, while he was sitting next to the child,

Schaffer walked in with Dr. Laughlin and announced, "We've come to take charge of the baby!" Schaffer then said he was going to take the child down to the special-care nursery and start feeding him intravenously. Owens asked him whether he had a court order. "I don't need it," Schaffer replied.

Owens grew menacing. "If you do anything to that child," he growled, "you're putting yourself at peril." Whereupon he dialed Andrew Mallor, who got into a heated exchange with Schaffer on the telephone.

At that point Schaffer left, Owens says, but came back a few minutes later with another pediatrician, who examined Baby Doe and declared that the child had already deteriorated beyond the point of resuscitation. She persuaded Schaffer to leave with her.

Within a short time, however, Schaffer reappeared in the doorway with an IV bottle in his hands. Owens says there is no doubt in his mind that Schaffer intended to "kidnap" the child.

Schaffer's version differs very little, except that he says he never actually told Owens he was going to remove the baby from the room. Schaffer recalls: "I told Dr. Owens that we were going to start an IV, that the chief of staff of the hospital had asked me to. The hospital was paralyzed, you see. It didn't seem to be able to act. On the other hand, I could. But if I'd just barged in there they probably could have got me on a kid-

napping charge."

In seeming contradiction, however, Schaffer admits he went so far as to place a telephone call to Riley Children's Hospital, asking whether they would send a helicopter for the baby if he resuscitated it with an IV.

Schaffer's ambiguity extends to whether he would have tried to overpower Dr. Owens to get at the child. First he says he doubts it. But then he adds passionately: "I probably would have started that IV, yes, sir. And I don't think it would have been advisable for anyone to try and stop me. I'd have gone past anyone who tried to interfere with my treatment of a critically ill baby." He knew that had he begun an IV, he might have been held in contempt of court. "I didn't care," he says, "because we have a judge in town who needs another job, and maybe when the next election comes, he'll get one. Why not subvert a judge's decisions? It depends [on] what's right and wrong."

**S**chaffer says he also had a "sadistic" reason for showing up, "to see Walt sweat a bit. I told him, 'Walt, what are you trying to prove by this?' He had been hovering over the baby for days like a mother bird, afraid somebody would come in and do something to it. That kind of behavior bothers me. I've hovered over a baby trying to save it. But why hover over it to

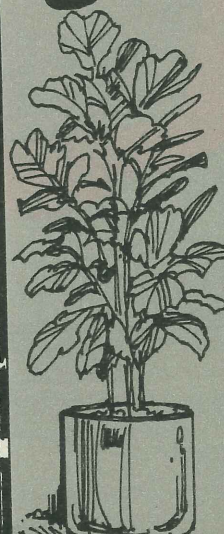
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Bloomington Hospital: Concerns about criminal liability.

make sure no one touches it?"

Whatever Schaffer's intentions may have been, while he was standing in the doorway with the intravenous bottle and tubing in his hand, the entire matter became academic.

At exactly 10:01 p.m., six days after his birth, Baby Doe died with the two doctors looking on. Cause of death: chemical pneumonia, due to the regurgitation of his own stomach acid.

An autopsy was conducted by John Pless, the Monroe County coroner. Dr. Pless discovered that there had been no enlarged heart; the X-rays had been misleading. Nor could he find any direct evidence of brain damage caused by oxygen deprivation. But the child did indeed have a tracheoesophageal fistula. The coroner says he has no doubt the child was, in medical vernacular, "a bad baby."

Pless, a pleasant, meticulous man, maintains an office on the first floor of Bloomington Hospital. He sits behind an oversized desk, where a large gray microscope and a desktop computer are the primary tenants. He discussed the autopsy one recent afternoon.

"The baby received oxygen immediately after birth; it just didn't breathe very well," he said. "That's crucial in this case. It suggests it was not a good baby. It was blue for at least two minutes; then it was very limp even after it pinked up.

"It doesn't surprise me that I didn't

see brain damage. It could have been there without my finding it. I suspect there may have been some. Many doctors will tell you they can resuscitate blue babies and there won't be residual brain damage. But they are talking about kids who are otherwise healthy, not Down's children with tracheoesophageal fistula. This baby just wasn't put together very well."

On the night of Baby Doe's death, Lawrence Brodeur was in the Atlanta airport, awaiting a connecting flight to Washington. He had to turn around and come home.

**I**t is likely to be years before the issues that were raised that night in Bloomington, Indiana, are settled to society's satisfaction. In response to the episode, the Reagan administration issued a series of federal fiats designed to ensure that virtually all handicapped babies, no matter how severe their disabilities, receive the medically indicated life-saving treatments. The quality of a child's future life was not to enter into the equation. These "Baby Doe" regulations, as they came to be called, were vigorously opposed by the medical community, which considered them an infringement on parental rights and doctors' discretion. A federal court ultimately ruled them invalid. But Congress thereupon passed legislation de-

continued on page 20

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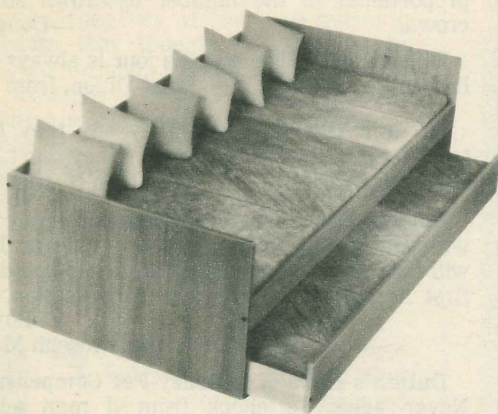
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## Baby Doe

continued from page 22

The judge says he's received a huge volume of mail. "Some say they wish they'd been allowed the same alternative with their children. Others say they wish I'd been hanged with the rest of Hitler's exterminators."

As for the Does, Judge Baker says: "They've resented comments about their moral character. They had a tragedy on their hands. It was their baby son who died, after all."

Teleatha McIntosh, one of the nurses who watched the Doe child die, found the whole affair extremely traumatic. "I feel that a terrible injustice was done," she says. "I couldn't sleep for a long time afterwards. Every time I closed my eyes, I'd see that baby lying there bleeding and fighting for breath. It was hard to get it out of my mind."

Bonnie Stuart, who also worked the fourth floor that week, says she, too, had insomnia. "It still seems like a nightmare to me. I still can't believe it happened in today's society. I said, 'This is wrong,' 50 times a night as I was taking care of him. He wasn't limp like they said. When I'd give him a shot of Demerol, he'd flinch. He'd open his eyes when I stroked his head. He looked like a perfectly normal little boy. Yes, he did have the eyes of a Down's child, but other than that he looked normal."

Dr. John Pless, the county coroner, says he personally feels the Does had a right to make the decision they did. "It took me a long time," he says, "to develop ideas of what I'd do if it was my child. I'd find it difficult to do what those parents did. But I feel they had the right to do it, and it's wrong for third parties to come in and say they made a bad decision afterwards."

The parents' attorney, Andrew Mallor, says the Does have never once regretted their action. "People get the image of a healthy baby lying in a crib starving and evil parents trying to do it harm. They don't understand this was a very, very ill baby, and in such cases it might be better to let nature take its course. They are as good a couple as you'll ever meet, and the question of what it was like to be confronted by this horror in what was to be a joyful moment has never been considered properly."

Nurse Dana Watters wrote a letter to Mrs. Doe after the episode. "I told her how badly I felt for them. She wrote back to say how much they appreciated my concern and to tell me how much it hurt to wake up in the middle of the night expecting a baby to cry and then to find no baby there."

**I**n the more than two years that have passed since the Doe child died, a number of things have happened to the people who fought over his fate.

Lawrence Brodeur took the case to the U.S. Supreme Court, arguing that although the child was dead, the issue of whether his life should have been ended needed to be resolved because it would come up again and again. In the autumn of 1983 the Supreme Court declared it a moot case and refused to hear it. Barry Brown, the Monroe County prosecutor who tried so vigorously to have Judge Baker's ruling overturned, was subsequently defeated in his race for the state legislature. He and Brodeur now share a private practice.

The nurses McIntosh and Stuart required several months of psychiatric counseling following the episode. The hospital provided it free of charge.

Judge Baker has a re-election campaign coming up in 1986. He believes his decision in the Doe case may harm him at the polls. He and Dr. Owens have become very good friends, to the extent that he recently brought his children over to Owens' house for a hayride.

Dr. Owens has also become quite close to the Does. When his own son died tragically many months ago, they were the first people to come by to console him.

The Does have continued to be very private people. Thus far they have not publicly revealed their feelings to anyone about what they went through. In April, 1984, Mrs. Doe gave birth to another child. It was a healthy baby girl. ■

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**RIGHT-TO-LIFE CASE****Race on to keep handicapped baby alive**

AP and UPI

BLOOMINGTON, Ind. — A severely retarded infant grew weaker Thursday as lawyers prepared to appeal a state Supreme Court ruling that allowed the parents to withhold feedings so the boy would die.

At the same time, at least 10 couples offered to adopt the boy, who is identified in court records only as "Infant Doe." He was born April 9 with Down's Syndrome, a condition that causes mental retardation and physical defects.

The boys' parents, after conferring with doctors, decided to forgo an operation to correct a deformity in the baby's esophagus. The unidentified couple's decision to withhold surgery and nourishment was upheld Wednesday in a 3-1 vote by the Indiana Supreme Court after an emergency hearing.

Monroe County prosecutors, seeking time to prepare their federal appeal, went to a special county judge Thursday to ask for a temporary restraining order allowing care and feeding of the baby. Their petition was denied.

"The parents love this child," said Andrew Mallor, the parents' attorney, adding the couple wants to be left alone "so they can live with the decision."

MONROE COUNTY Prosecutor Barry Brown said the appeals work was a race against the baby's failing health. Bloomington Hospital refused to make the boy's condition public.

"(The child) is at this very moment at Bloomington Hospital starving to death," Deputy County Prosecutor Larry Brodeur had told the state's highest court Wednesday. The infant has "a constitutionally guaranteed right to live."

Brodeur was appointed legal guardian of the baby Thursday, replacing a guardian named earlier.

Brown said the federal appeal would argue the baby had been denied his constitutional right to due process.

AMONG THOSE offering to adopt the baby were Mike Lorentay, who teaches the printing trade to the retarded in Edmonton, Alberta, and from Shirley and Bobby Wright of Evansville, Ind.

"I believe that every person, no matter who or what their ages, has a right to live," Lorentay said. "If need be, I'll pay for the operation. I'm not well off, but I'd pay for it and bring the baby back to Canada."

Wright said she and her husband had hired Jim Böpp, an attorney with ties to the Right To Life movement, to seek the adoption.

Hundreds of residents called Indiana Right to Life offices in Bloomington and Indianapolis to express outrage at the Supreme Court decision.

# Let Malformed, Retarded Infant Die, Indiana Court Rules

INDIANAPOLIS (AP) — A mentally retarded infant who can't eat because of a birth defect will be allowed to die instead of getting an operation to correct the problem.

After an emergency hearing Wednesday, the Indiana Supreme Court voted 3-1 not to interfere with a decision by the child's parents to forego treatment for their 6-day-old son, who suffers from Down's syndrome.

Lawyers for the unidentified parents from Bloomington said they were pleased with the decision.

In addition to Down's syndrome, the little boy has an improperly formed esophagus that does not allow food taken through his mouth to reach his stomach.

Doctors advising the boy's parents said they could perform surgery to correct the defect or do nothing. The parents chose to withhold all food and drink.

The hospital asked for a legal ruling, and two Bloomington judges upheld the parents' stand.

But Monroe County Prosecutor Barry Brown and Phillip C. Hill intervened. Hill was appointed guardian for the child and he and Brown asked the state Supreme Court to override the judges' decision and order either surgery or intravenous feedings for the child.

Justice Roger O. DeBruler of the high court said he was concerned about judges second-guessing doctors on medical matters.

It "seems almost preposterous that courts in our society should be given that kind of authority," he said, and voted alone to order the baby kept alive.

Deputy Prosecutor Lawrence Broder urged the court to act because the child "is at this very moment at Bloomington Hospital starving to death." He said the infant has "a constitutionally guaranteed right to live."

Hill warned "if this court does not act today, this child will be condemned to death ... He will die. He will lose his right to appeal. That is irreversible."

Andrew Mallor, a Bloomington lawyer representing the parents and one of the judges, disagreed.

"We are dealing not with a condemnation of death," he said. "We are dealing with two appropriate methods of treatment for a very sad case."

Beyond the legal aspects of the case, Mallor said, there is a very practical problem: In order for the surgery to be effective, it should have been done within 24 hours of the baby's birth. Even then, there was only a 50 percent chance of success, he added.

"There are signs that nothing is going to make a difference at this point."

Chief Justice Richard M. Givan and Justices Dixon W. Prentice and Alfred J. Fivarnik voted to deny the order. DeBruler said he would have granted a writ to preserve the child's appeal rights.

Meanwhile, a couple in Evansville said Wednesday they would like to adopt the dying baby.

"How can they let a little baby starve to death? In my mind I can't comprehend that," said Shirley Wright, whose 3-year-old daughter also has Down's syndrome. She said she heard about the case on the radio and with her husband, Bobby, hired a lawyer to contact the Bloomington couple.

For Publication  
April 17, 1982

### THE DEATH OF INFANT DOE

By James Bopp, Jr.

Infant Doe did not have to die. Ordinary medical treatment and care would have allowed Infant Doe the chance to live his life--loved by his parents in a home surrounded by caring people.

Bob and Shirley Wright know about raising a Down's Syndrome child. Bobbi, their youngest at three, is afflicted with Down's Syndrome. When she was born, they, too, were anguished. Bobbi has now provided them all the joy--and heartache--of any normal child. Bob and Shirley were willing--no, deeply wanted--to adopt Infant Doe so that he too would know the joys--and sorrows--of life.

Infant Doe never had that chance. Drugged from almost the moment of birth, Infant Doe never really knew the world outside the womb. Inside the womb, his mother, who we may never know, cared for him, felt his movement and had great hopes for him. Born on Friday, the parents were overwhelmed with grief, guilt, and hopelessness. The joyously awaited experience turned into one of catastrophe and profound psychological threat. Infant Doe suffered from Down's Syndrome, a condition which can lead to mental retardation.

Infant Doe, however, did not die from Down's Syndrome. Infant Doe died because his parents and doctor refused to feed him and give him fluid to drink. Infant Doe died from the effects of starvation and dehydration. Infant Doe suffered from a physical defect which often accompanies Down's Syndrome, the esophagus and wind pipe were joined. Feeding by mouth was impossible without surgery. But it was not this physical defect, either, which resulted in Infant Doe's death. The parents, offered the choice by their physician between treatment and no treatment, refused medical care for Infant Doe. The attending physician, the hospital, and several state court judges agreed. Infant Doe would receive no medical care, no food and no liquid. Infant Doe died in six excruciatingly long days.

Not everyone agreed with this decision to condemn Infant Doe to death by starvation. A pediatrician, Dr. James Shaeffer, called in to advise the parents on medical treatment, urged that the child's physical defect be repaired. This physical defect is routinely handled by Riley Children's Hospital in Indianapolis, only sixty miles away. Infant Doe could be fed intravenously and the operation performed within twenty-four hours. This surgery is ordinary medical treatment with a relatively low complication rate. Infant Doe's prognosis was good.

Any other child born with such a physical defect would have been rushed to surgery. Infant Doe, because he suffered from Down's Syndrome, was not. Because of his handicap, the parents refused treatment and the judge ruled that the parents had the "right to choose."

Barry Brown also did not agree. As Prosecutor for Monroe County, Indiana, he filed suit to declare that Infant Doe was neglected, having had no food or drink for three days by then, and urged the court that normal medical treatment and care be afforded Infant Doe. The judge denied this request and the Indiana Supreme Court, two days later, refused to interfere.

Infant Doe had now been without food and water for five days. The Supreme Court decision, for the first time, made the news public. This was the first non-confidential hearing and the public found out about the starving Infant Doe.

Phones began to ring. People throughout Indiana, and the country, as the news spread, were shocked and appalled. Calls to the Indiana Supreme Court expressed outrage, calls to public officials of all kinds, including the Governor, demanded that something be done, and calls to the Prosecutor commended his actions and offered to adopt Infant Doe. I, too, was called. Concerned people throughout the State wanted to know what could be done. The reports were still very sketchy and incomplete.

Bob and Shirley Wright of Evansville, Indiana, did not agree with the decision either. They asked everyone--what can be done to save this child, we will adopt him. On Thursday morning, the sixth day of Infant Doe's life, the Wrights contacted me. Can we do anything?

Six hours later I filed a petition with the Monroe County Judge to appoint the Wrights guardians of Infant Doe. They promised to keep and care for him. Dr. Shaeffer would arrange medical care. The feeding of Infant Doe would begin. The Wrights would adopt Infant Doe. The judge denied the request.

The hearing before the judge on the Wright's petition began at 5:00 p.m. An unreal atmosphere enveloped the court as all but the judge, court personnel and lawyers were excluded. The press, the people's eyes and ears, were ordered out. The justification for the parents' action was given by their lawyer. The parents had been advised by their physician that they had two alternate courses of treatment, treatment and no treatment. The parents chose no treatment, thus Infant Doe was being treated by the alternative of no treatment. Non-treatment became treatment.

While the Wrights were entitled to "their beliefs", according to the parents' lawyer, the parents were entitled to their "right to choose." The right to choose death by starvation for their son. Why not allow the Wrights to care for Infant Doe, feed him, give him medical care? Infant Doe, said the parents' lawyer, is now in extremis. "There is no reason to change your order, Judge, since Infant Doe will die anyway."

The parents' lawyer and the judge were trapped by their own course of action. Only Infant Doe's death would justify their choice. Infant Doe was not to be fed even if someone else would adopt and care for him. Infant Doe would not even be fed temporarily so that the U.S. Supreme Court could hear the case. The parents and the judge would not admit that they were wrong, that admission being too great a burden to bear.

Infant Doe had almost died that afternoon, after the judge had refused temporary feeding so that the prosecutor could appeal to the U.S. Supreme Court, but before the Wrights' petition was heard. Suffering from severe dehydration, pneumonia and weakened by starvation, Infant Doe stopped breathing. Miraculously, he spontaneously began again. The Wrights' petition would be heard because Infant Doe still lived. Even that faint hope of help for Infant Doe was dashed.

Even though Infant Doe's life was measured in only hours, the prosecutor prepared his appeal to the U.S. Supreme Court. All legal avenues in Indiana were exhausted. A private plane was volunteered. They must be in Washington at 9:00 a.m. Friday, when the U.S. Supreme Court offices opened. Infant Doe might not have a minute longer.

When the prosecutor's men got off the plane in Washington, D.C., Infant Doe was dead. Without food, drink or medical care, Infant Doe died at 10:03 p.m., only five hours after the Wrights had been denied the opportunity to adopt their third child.

The legal system failed Infant Doe. The parents, consumed by grief and anguish, chose for Infant Doe to die. They deserve our pity and sorrow for the burden they will carry. The physician, however, should not have failed Infant Doe. Non-treatment is not treatment. Infant Doe was his patient, he should have helped. Ominously, the courts also failed Infant Doe. Empowered by the Indiana legislature to protect the young and helpless, the courts ordered no medical treatment or care for Infant Doe. The courts were intended to be the ultimate protectors for the neglected and abused, instead, they were the instruments of Infant Doe's death.

I am sorrowed by Infant Doe's death to the bottom of my soul, but everything has a purpose. Infant Doe does not have to die in vain. He is the person, now the symbol, of those who we must protect. Everyone must be entitled to ordinary medical treatment and nourishment. A child must not be killed because he is handicapped. We must insure that Infant Doe died so that others, we will never know, will live.

James Bopp, Jr., is an attorney in Terre Haute, Indiana, and represented Bob and Shirley Wright in their attempt to adopt Infant Doe. He is also General Counsel for the National Right to Life Committee.

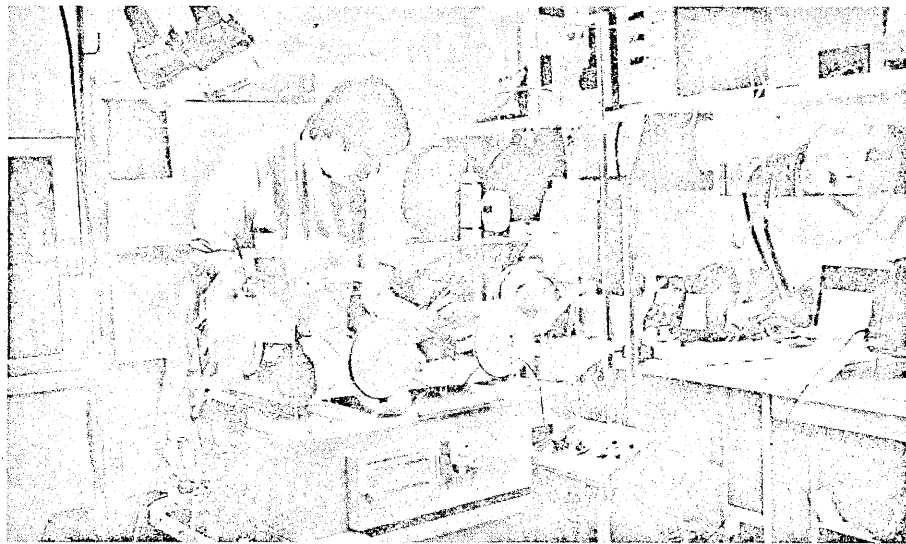
## The Stormy Legacy of Baby Doe

*Should the Government try to save severely afflicted infants?*

On April 9, 1982, an infant who became known to the world only as Baby Doe was born in Bloomington, Ind. He had an incomplete esophagus and Down's syndrome, which causes moderate to severe mental retardation. Thanks to advances in neonatal medicine, surgeons could ensure Baby Doe's survival by attaching his esophagus to his stomach, but nothing could be done to prevent retardation. His parents were confronted with an agonizing dilemma: to assent to an operation that would save the life of a child who could be hopelessly retarded, or to allow him to die of starvation. Against

1982, the department informed the nation's 5,800 hospitals that they could lose federal funding if they withheld treatment or nourishment from handicapped infants. This edict was followed by a tougher regulation requiring hospitals to post large signs in public places bearing the inscription "Discriminatory failure to feed or care for handicapped infants in this facility is prohibited by federal law." The posters provided the number of a 24-hour, toll-free hotline for anonymous informers who wanted to report violations to federal investigators.

Doctors and medical organizations



A doctor and nurse treating an infant in a neonatal intensive-care unit in New York City

*Resentment by physicians that the Administration was questioning their competency.*

the wishes of their pediatrician and hospital, they chose the latter. The parents' right to this choice was twice challenged in the courts by the hospital and twice upheld. On April 15, Baby Doe died.

His legacy is today one of the most fiercely debated controversies in medicine. At issue: how to protect the rights of severely handicapped infants, and what role the Federal Government should play. Locked in the battle are three factions—doctors, handicapped citizens' groups and right-to-life organizations. Last week, as the Reagan Administration reviewed its stand, it came under concerted attack by the medical profession in the form of two blistering editorials in the prestigious *New England Journal of Medicine*.

The Baby Doe debate was ignited by the President. Outraged by the case, Reagan ordered the Department of Health and Human Services to ensure that handicapped infants would receive proper medical care even if their parents or physicians were willing to let them die. In May

were outraged by this unprecedented intrusion of the Federal Government into matters that traditionally have been settled privately between physicians and parents. The new rule implied that doctors and parents could not be trusted to act in the best interest of a handicapped child. No less infuriating to physicians was the rule's assumption that all congenital defects could be handled in the same manner, that any child's life, no matter how tenuous, painful and ill-fated, should be sustained for as long as is technically possible.

The American Academy of Pediatrics, the American Hospital Association and a number of other professional organizations took the HHS to court over the Baby Doe rule and won. District Court Judge Gerhard Gesell last April found the regulation to be "arbitrary" and "ill-considered." Three months later, HHS issued revised regulations, which conceded that there was no need to impose "futile therapies" on terminally ill infants.

The Government argues that the in-

former system developed by the hotline has been effective. As of last week, there had been 33 accusations that hospitalized infants were not receiving proper care. In eleven cases, the Government dispatched teams composed of doctors and civil rights investigators. The squads found nothing to criticize on eight visits, but were able to help save the lives of three handicapped infants whose doctors seemed to be unaware of new techniques for treating birth defects.

The pediatricians and allied medical groups argue that the best way to help such afflicted babies is by better educating doctors about medical advances, not by sending in federal watchdogs. Hospitals charge that some of the investigative teams disrupted neonatal clinics. Such disturbances led the A.A.P. to protest that "the Government's 'remedy' is potentially harmful to the very infants it seeks to protect."

As an alternative to direct federal interference under the Baby Doe rule, the pediatricians, the A.H.A. and five other medical groups propose that all hospitals be required to create "infant bioethical review committees" to protect the rights of handicapped newborns. These committees, composed of medical experts, laymen, clergy and lawyers, would be consulted in any decision to forgo treatment. The groups would also try to resolve any conflict between parents and doctors over how to proceed. Should parents refuse to approve treatment that would clearly benefit their child, the committee could ask state agencies and courts to appoint a guardian.

Such an approach is unacceptable to groups representing the handicapped and right-to-life organizations. "The problem is how to ensure the rights of the handicapped to treatment, when the parents, doctors and the hospital agree not to provide it," says Gary Curran of the American Life Lobby. Another worry is that a bioethics committee could not act quickly enough. Warns Paul Marchand, of the Association for Retarded Citizens: "If these infants are not treated within days, hours, they will die."

The Department of Health and Human Services has reservations about the proposal to create ethical review committees. "The problem is there wouldn't be any enforcement," says John Svahn, who was recently promoted from HHS Under Secretary to Assistant to the President for Policy Development. The department hopes to come to a final judgment in the next few weeks. If the hotline and what some doctors deride as investigative "goon squads" are not eliminated, the medical organizations have threatened to take the Reagan Administration to court again.

—By Claudia Wallis. Reported by Anne Constable/Washington and Sheila Gribben/Chicago

# Baby Doe Abandoned by Rights Hypocrites

Washington Post Writers Group

WASHINGTON — Civil rights "activists," so active in denouncing President Reagan, have not noticed, or will not acknowledge, that he is significantly expanding civil rights protections. That is the importance of cases like that of "Baby Jane Doe" in New York.

The government is seeking medical records in the case of the infant born with spina bifida and excessive brain fluid. Without surgery the baby is expected to die within two years. The parents oppose surgery. Doctors say — guess, really — that the child would be "severely" retarded and would die as a young adult. The federal government may seek treatment the parents oppose.

The administration is not acting on an ideological quirk. It is giving a reasonable interpretation to a civil rights law, Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination solely on the basis of handicap. The administration is not trying to sever Section 504 from medical judgment. There is no notion of an obligation for futile treatment that merely prolongs dying or extends life a short span.

But treatment should not be withheld to cause the death of a newborn because parents decide, on the basis of doctors' guesses, that the child's life would be inconvenient, disappointing or without acceptable "quality."

After parents and doctors agreed in Indiana in 1982 to starve a Down's syndrome baby rather than perform routine

surgery, Reagan ordered regulations requiring the posting in hospitals of notices that discriminatory denial of care to handicapped infants is prohibited. A hotline was established for reporting violations.

The New York Times, which favors aggressive federal action to protect the right to vote or to a safe work place, denounces the government as "Big Brother" when it moves to protect an infant's right to life. If a parent and an employer decided to employ the parents' healthy child at less than the minimum wage, the Times would demand a federal posse. But when the government considers intervening to prevent parents and doctors from causing death by withholding treatment, the Times champions parental sovereignty.

Such sovereignty is highly conditioned. Parents can not abuse or neglect their children, or keep them from schooling, or prevent them from receiving certain vital medical care, such as transfusions, on religious grounds.

The Wall Street Journal, which at least has a crazy consistency (it doesn't much like government, the Pentagon excepted) denounces the administration for "harassment" of parents and doctors and for expanding "the role of Washington in our lives." The Journal wants the rights of handicapped newborns allocated by the private sector, by parents and doctors.



George Will

But surely even conservatives of the Journal's stripe can concede that the federal government, in addition to running the Navy, can legitimately protect babies from being condemned because of imperfections.

Many editorialists insist on deference toward doctors' judgments. In the Indiana case, a doctor testified that the baby should die because the baby would never achieve a "minimally acceptable" quality of life. The doctor decreed that "some" Down's syndrome persons are "mere blobs; and that he had never known a Down's syndrome person "able to be gainfully employed in anything other than a sheltered workshop . . . that could be self-supporting . . . These children are quite incapable of telling us what they feel, and what they sense . . ."

The moral squalor of that statement (should life-saving treatment be denied to all economically marginal persons?) is exceeded by its ignorance: I'll introduce the doctor to Down's syndrome citizens — sorry, doctor, that's what they are — who work outside sheltered workshops and who can tell what they feel and sense about people like him. Clearly, some doctors claim authority concerning matters that are in no sense medical. Note the doctor's opinion about the "acceptable" — to whom? the AMA? — quality of life.

A person who calls the police to protect a child that is being abused next door is called a good citizen. A nurse who tells the government that a baby is suffering the ultimate abuse is denounced by editorialists as a "spy" or "police informant" or "busybody."

A professor writes that the hospital notice and hotline "insult" all doctors as potential child abusers. But do child-abuse laws insult all parents? Editorialists who have favored sending civil rights enforcers, even the Army, into the South now express horror about "Baby Doe squads" descending on hospitals.

Why the hysteria? Perhaps it is because editorial writers consider doctors as peers — fellow professionals and equally infallible. It is one thing to urge federal enforcers on businessmen, but restricting the discretion of professionals is an affront.

Furthermore, many members of the social stratum from which editorial writers come can not cope with the fact of permanent defects, especially in children, defects that neither a new law nor a new antibiotic nor a new curriculum can cure. Parents who conjugate French verbs for their superbabies are unnerved by what they think is the meaninglessness of a life that will not include reading New York Times editorials.

But American history is a story of progressive inclusiveness as rights have been extended beyond healthy, white, property-holding males. America today is on the threshold of another great inclusion, that of handicapped, and especially mentally handicapped, persons.

This is Ronald Reagan's doing, and he is getting neither help nor credit from the self-appointed custodians of the nation's conscience regarding civil rights.

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