

●LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS. Edited by A. Edward Doudera, J.D., and J. Douglas Peters, J.D. (AUPHA Press, Ann Arbor, Michigan) (1982) 344 pp., \$27.00.

### Human Experimentation

Freedman B, *The Validity of Ignorant Consent to Medical Research*, IRB 4(2): 1-5 (February 1982) [10-277].

Holder AR, *Contraceptive Research: Do Sex Partners Have Rights?* IRB 4(2): 6-7 (February 1982) [10-278].

Mishkin B, *Whistleblowing In Biomedical Research: Report from a Workshop*,

IRB 4(2): 8-9 (February 1982) [10-279].

**First Biennial Report on the Adequacy and Uniformity of Federal Rules and Policies, and Their Implementation for the Protection of Human Subjects in Biomedical and Behavioral Research**, 47 Fed. Reg. 13272-13305 (March 29, 1982) [10-191]. Pursuant to provisions of the Public Health Service Act, as amended, each federal agency affected by the recommendations, as developed in the mandated biennial reports of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Re-

search, is required to publish its responses in the Federal Register. This report is by the Secretary of the Department of Health and Human Services for 19 affected agencies.

### Informed Consent

McClellan FM, *Informed Consent to Medical Therapy and Experimentation: The Case for Invoking Punitive Damages to Deter Impingement of Individual Autonomy*, JOURNAL OF LEGAL MEDICINE 3(1): 81-115 (March 1982) [10-247].

Soe M, Leng GA, *Should Consent Be Informed Consent? Legal and Medical Viewpoints*, in CURRENT PROBLEMS IN LEGAL MEDICINE (Medico-Legal Society of Singapore) (1981) [10-289].

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media coverage will ultimately move us to some kind of (unwritten) resolution, or we will eventually learn to accept our present situation and continue to use caution in making life and death decisions.

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**Editors' Note:** When Sheila Taub's article on Withholding Treatment from Defective Newborns was published in the February 1982 issue, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was holding public hearings on the same subject. In April 1982, newspapers around the country carried stories about "Infant Doe," a baby with Down syndrome and a repairable deformity of the esophagus, whose parents refused the surgery to repair the deformity, to permit the child to eat, and, ultimately, to live. Instead, the child died — after the Indiana Supreme Court had upheld the parents' decision, but before county prosecutors were able to get the case heard by the United States Supreme Court. In an April 1982 column, George F. Will noted:

There is no reason — none — to doubt that if the baby had not had Down's syndrome the operation would have been ordered without hesitation, almost certainly, by the

parents or, if not by them, by the courts.

It is hard to refute his conclusion. But what about the issues raised by Dr. John Freeman — a call for justice, a concern for the potential outcome and the feelings of all involved? What about Dr. Ann Fletcher's implication that futile care should not be given — even if parents request it, since to do so is, in these times of limited neonatal intensive care beds, to deny a potentially life-saving "bed" to another critically ill newborn.

In response to the Indiana case, President Reagan reportedly sent a memo to Attorney General William F. Smith and Department of Health and Human Services Secretary Richard S. Schweiker asking them to "remind hospitals and other health care providers that Section 504 of the Rehabilitation Act of 1973 forbids recipients of federal funds from withholding 'from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps.'" The notice sent by the Director of the HHS Office for Civil Rights to 6,800 hospitals said:

Under §504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life threatening condition if 1) the withholding is based on the fact that the infant is handicapped and 2) the handicap does not render treatment or

nutritional sustenance medically contraindicated.

Undoubtedly, this announcement will not help an already troublesome problem. The American Hospital Association, for example, responded by claiming that the HHS action will "create an adversarial relationship between hospitals and parents who elect not to have complicated surgery performed on their children." Treating or not treating newborns suffering from severe birth defects has been a question facing physicians, nurses, families, and, to some extent, lawyers for many years. Most of them can relate to the recent newspaper accounts of Brian West, an infant, now some 20 months old, who was born with the same maladies as Infant Doe — Down syndrome and esophageal atresia. One recent account described Brian as follows:

He weighs 16 pounds and cannot walk, talk or eat. He has had two major operations, one heart failure, collapsed veins, stomach acid spills on his skin, regular injections of nutrients and antibiotics in nearly every part of his body, several weeks of being bound hand and foot, and has a tube permanently attached to his stomach so he can be fed.

Brian's parents were reportedly "blocked in their effort to let their baby die" — blocked by a system that required that they submit to publicity and incur extensive legal expenses in a battle they could have easily lost. Instead, they pleaded no