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THE LIVING DEAD: ANENCEPHALY AND ORGAN DONATION

Legislators are considering whether the anencephalic¹ child, though its heart is beating and lungs are breathing, should be considered "dead" for purposes of organ transplantation. This is because the common law, in the opinion of many, renders the wrong result.² Statutes on the issue offer little assistance.³ Consequently, sympathetic legislators are drafting proposals which they hope will create a narrow exception to the current laws so that the anencephalic neonate may again become a viable source of donor organs.⁴

This note will examine the legal and ethical dilemmas in such organ donation and will examine alternatives including

1. See *infra* note 7 and accompanying text.

2. Under the common law, the anencephalic child is an unsuitable organ donor because at the time the organs are salvageable, the infant fails to meet the criteria for cardiopulmonary death. See *infra* notes 52-59 and accompanying text. See also PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DEFINING DEATH 135 (G.P.O. 1981).

The courts long ago established the "the cessation of life" was to be judged primarily by "a total stoppage of the circulation of the blood," in the words of *Black's Law Dictionary*. *Black's* - which is not usually a leading legal authority - is associated with this "definition" because the dictionary language was repeated *in haec verba* in a number of judicial opinions. Indeed, this interpretation was reiterated despite the development of medical techniques that could revive respiration and circulation in a corpse.

Id.

3. See *infra* note 51 and accompanying text. Statutes require that death be determined by "generally accepted medical practices." See UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 312 (Supp. 1989). Due to the unique nature of anencephaly and the problems attendant with the determination of "brain death" in infants, the anencephalic's organs are too deteriorated by the time a determination of brain death can be made. See Blakeslee, Law Thwarts Effort to Donate Infants' Organs, N.Y. Times, Sept. 9, 1986, at C1, col. 1.

4. See *Committee Report, The Anencephalic Fetus and Newborn as Organ Donors*, N.Y. ST. J. MED., July 1988, at 360, 361 [hereinafter *Committee Report*]. It is clear from this Report that such organ donation has not always been problematic. *Id.* at 361-64. The Report reveals that anencephalics have frequently been used as a source of donor organs. *Id.* at 361. The Report discusses many documented anencephalic transplants for the purpose of examining the ethical considerations of the surgeons involved in the procedure. Kantrowitz, the surgeon who performed the very first modern transplant in 1966, used an anencephalic as a donor source. *Id.* at 361. Kantrowitz asserted that "anencephalic newborns were a reasonable choice as donors for babies." *Id.* at 361.

an assessment of proposals by California Senator Milton Marks⁵ and New Jersey Assemblyman Walter M.D. Kern, Jr.,⁶ both of which are currently under consideration in their state's legislatures.

Anencephaly is a gross birth defect which prevents the formation of the upper hemispheres of the brain, allowing formation of only the brainstem.⁷ Consequently, the newborn

5. S. 2018, 1985-86 Leg., 1986 Sess., (Cal. 1986) (subsequently revised and under consideration currently).

6. N.J. Bill A-963, 40th Leg., 202d Sess., (1988) (introduced pending technical review by the legislative counsel).

7. See Medical Task Force on Anencephaly, *The Infant with Anencephaly* (Draft), April 12, 1989, (on file at New York Law School Journal of Human Rights) (this document presents a consensus, limited to medical issues, of organizations of physicians caring for fetuses and infants with anencephaly). See also D. SMITH, *RECOGNIZABLE PATTERNS OF HUMAN MALFORMATION* (1976).

Anencephaly represents a defect in closure at the anterior portion of the neural groove. The secondary consequences are as follows: (1) the unfused forebrain develops partially and then tends to degenerate; (2) the calvarium is incompletely developed; and (3) the facial features and auricular development are secondarily altered to a variable degree, including cleft in the palate, frequent abnormality of the cervical vertebrae, and occasional incomplete development of the anterior pituitary.

Id. at 368. See also R. GOODMAN & R. GORLIN, *THE MALFORMED INFANT AND CHILD* (1983).

Anencephaly has been classified into two major types: *holoacrania*, in which the defect extends through the foramen magnum, and *meroacrania*, in which the foramen magnum is not included in the opening. The cranial vault is absent; only the basal portion of the frontal, parietal, and occipital bones are present. The CNS [*craniorachischisis*, total dysraphism] shows varied pathology depending on the extent of the lesion in the neurocranium and the gestational age. The cerebral hemispheres and cerebellum may be rudimentary or absent. The remaining cerebral tissue is distorted and mixed with an angiomatous stroma. The angioneural tissues are covered by a membrane. Due to small orbits, the eyeballs protrude. There are variable alterations in the facial skeleton and the hard palate is usually malformed. Cleft palate and facial duplication may be noted in some cases. A number of anencephalics have spinal retroflexion. Malformations of the limbs, thoracic cage, abdominal wall, gastrointestinal tract, and genitourinary system are relatively frequent in anencephaly . . . The clinical features are so characteristic that anencephaly cannot be confused with other disorders.

Id. at 40 (emphasis in original text). See also D. BERSMA, *BIRTH DEFECTS COMPENDIUM* (2d ed. 1979).

Clinical Findings: Cranial vault deficient with frontal, parietal and occipital bones present only in their basal portions. Basal bones are abnormal with small orbits causing protrusion of eyes. Exposed neural tissue pervaded by angiomatous stroma filling the open cranial defect, usually covered by a thin membrane (arachnoid) continuous with

has no cognitive capability,⁸ but does have cardiopulmonary functions. The infant is, in effect, a biological human but not a sentient one.⁹ Most anencephalics do not survive to birth,¹⁰ but of those that do, the life expectancy is usually not more than two days,¹¹ though a few have lived two months.¹² Standard treatment is comfort care.¹³ Possibly these infants could live longer but aggressive treatment is routinely withheld.¹⁴

surrounding hair-bearing skin. Generally stillborn or short-lived.

Id. at 83. See also President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, 181 (1983) [hereinafter LIFE-SUSTAINING TREATMENT].

The fourth source of permanent unconsciousness is congenital hypoplasia of the central nervous system (anencephaly). Various degrees of hypoplasia and dysplasia are possible and some engender brief vegetative life without development of any mentation or cognition. Usually such conditions are apparent because of abnormalities of the cranium at birth. Sometimes the infant is fairly normal, however, and only the failure to achieve the usual developmental landmarks or the appearance of other medical complications leads to detection. Most babies whose anencephaly precludes development of any consciousness die within a few days of birth, and none survive for more than a few months. This condition afflicts one of every 850 births, for an annual incidence of 4000 in the United States.

Id. (footnote omitted).

8. *Id.*

9. See Caplan, *Should Foetuses Or Infants be Utilized as Organ Donors*, 1 BIOETHICS 119, 138 (1987) [hereinafter Caplan]. "These [anencephalic infants] cannot be said by any stretch of the imagination to have had desires wishes, or thoughts . . . [T]here is no meaningful sense in which anencephalic infants can be said to have any of the properties associated with interests, self-respect or personal dignity." *Id.*

10. See Walters & Ashwal, *Organ Prolongation in Anencephalic Infants: Ethical & Medical Issues*, HASTINGS CENTER REPORT, Oct.-Nov. 1988, at 19 [hereinafter Walters]. ("Although most anencephalic infants are stillborn, between 25 and 45 percent are live births.")

11. *Id.* at 19, col. 2. Approximately 40 percent of these infants who are born alive survive at least twenty-four hours. Of these survivors, one of three will be living at the end of the third day and one of twenty will live to at least seven days. *Id.* (citing Baird and Sadovnich, *Survival in Infants with Anencephaly*, 23 CLINICAL PEDIATRICS 250 (1988)).

12. *Id.* at 19, col. 2. See also, Caplan, *supra* note 9, at 122; Baird & Sadovnick, *Survival in Infants with Anencephaly*, 23 CLINICAL PEDIATRICS May 1984 at 268; Botkin, *Anencephalic Infants as Organ Donors*, 82 PEDIATRICS Aug. 1988 at 250; Abraham, *Anencephalic Donor Program Symied in Controversy*, Am. Med. News, Sept. 23, 1988, at 1, col. 2 [hereinafter *Symied*].

13. Walters, *supra* note 10, at 19, col. 3.

14. *Id.* See also LIFE SUSTAINING TREATMENT, *supra* note 7, at 181 (the President's Commission considers anencephaly as a reason for withholding life sustaining treatment).

Legal issues arise when the parents of an anencephalic child wish to donate the infant's organs. This is because the child fails to meet generally accepted practices for determining death.¹⁵ The problem is that this donation is a non-therapeutic and non-consensual organ extraction from an incompetent, and the extraction would have to be performed before a conclusive determination of "brain death" could be made. So framed, there are two broad legal issues. First is whether parental consent is acceptable when the procedure in no way benefits the child;¹⁶ and second, because of the inability to conclusively determine death according to standard medical practices,¹⁷ whether the removal of the child's organs is child abuse, murder or euthanasia.¹⁸ These issues will be examined separately after first reviewing the ethical considerations both supporting and opposing anencephalic organ donation.

I. THE ETHICAL DEBATE

The reasons supporting anencephalic organ donation¹⁹ always begin with the distraught parents wishing to salvage some good from the tragedy of their anencephalic infant's

15. See *infra* notes 60-67 and accompanying text.

16. Removal of the anencephalic's organs may hasten or proximately cause the child's death. See *infra* notes 86-89 and accompanying text. See also *infra* note 17 and accompanying text.

17. See *infra* note 51 and accompanying text.

18. See *Committee Report, supra* note 4, at 364. "[P]ublic debate on the use of anencephalics as organ donors has not yet occurred, and . . . the removal of organs from such newborns is the proximate cause of death and therefore legally constitutes homicide and ethically constitutes euthanasia." *Id.* (quoting R. Cranford, *Medical Ethics / Vegetative State*, presented at the Annual Meeting of the American Academy of Neurology, April 1987, New York City). See also, Cranford & Roberts, *Use of Anencephalic Infants as Organ Donors: Crossing a Threshold*, *PEDIATRIC BRAIN DEATH AND ORGAN/TISSUE RETRIEVAL* 194 (H. Kaufman ed. 1989) [hereinafter *Crossing a Threshold*].

19. In addition to the reasons supporting anencephalic organ donation presented, a number of additional reasons are offered: Anencephalics are permanently unconscious; the diagnosis can be made with 100% certainty (unlike chronic vegetative state, i.e. permanent coma); the condition is easily recognizable by parents and others; and, these patients are truly dying (unlike the chronic vegetative state) because the overwhelming majority do not survive more than a few days. See *Committee Report, supra* note 4, at 364.

birth.²⁰ Anencephalic "Baby Gabrielle's"²¹ parents wanted to see that their baby would "touch others and contribute to life in some meaningful way."²²

While permitting the family to donate the anencephalic's organs helps mitigate their despair, most of all, such a donation provides the waiting recipients with "the gift of life."²³ This is sometimes referred to as the beneficence²⁴ rationale and is the most fundamental reason supporting anencephalic organ donation.

Anencephalic organ donation has only become an issue because medical technology has progressed far enough to provide hope for an infant born in need of a heart, liver, or kidney transplant.²⁵ However, there is a severe shortage of infant size organs.²⁶ This shortage is more severe than it is for children and adults.²⁷ Due to this shortage, most of these

20. See Harrison, *Organ Procurement for Children: The Anencephalic Fetus as Donor*, 2 LANCET 1383 (1986) ("to salvage from their tragedy the consolation that their loss can provide life to another child." *Id.* at 1385.); See generally Landwirth, *Should Anencephalic Infants Be Used As Organ Donors?*, 82 PEDIATRICS, Aug. 1988 at 257, 258 [hereinafter Landwirth].

21. See Scott, *Death Unto Life: Anencephalic Infants as Organ Donors*, 74 VA. L. REV. 1527 (1988) [hereinafter *Death Unto Life*]; See *Committee Report*, *supra* note 4, at 360; Annas, *From Canada with Love, Anencephalic Newborns as Organ Donors*, HASTINGS CENTER REPORT, Dec. 1987, at 36, 38 [hereinafter Annas].

22. *Baby Without Brain Kept Alive to Give Heart*, N.Y. Times, Oct. 19, 1987, at A1, col. 4, A1, col. 6 (quoting Dr. Tim Frewen, Chief of Pediatrics at Children's Hospital in London, Ontario).

23. See Walters, *supra* note 10, at 19, col. 2. Theoretically, a single anencephalic infant with healthy thoracic and abdominal organs could supply vital organs to save the lives of two other infants (one needing a heart and another a liver) and enhance the lives of several others (who need kidneys, corneas, and various transplantable tissues). *Id.*

24. Landwirth, *supra* note 20, at 258; see also T. BEAUCHAMP & L. WALTERS, CONTEMPORARY ISSUES IN BIOETHICS 28 (2d ed. 1982).

25. Landwirth, *supra* note 20; Capron, *Anencephalic Donors; Separate the Dead From the Dying*, HASTINGS CENTER REPORT, Feb. 1987, at 5; see Botkin, *supra* note 12, at 250.

26. See *Committee Report*, *supra* note 4, at 360. The need for small organs is considerable. In the United States, approximately 300 to 500 children die annually of end stage renal disease and about 400 to 800 die at birth or shortly thereafter of certain forms of congenital heart disease. *Id.* See also Botkin, *supra* note 12, at 250.

27. See Caplan, *supra* note 9, at 120.

The shortage of organs and tissues available from human sources for infants is far more severe than the serious shortfall that exists for children and adults. The small size of newborns means that, for the most part, only organs from other infants can be used for transplantation. The gap

potential recipient infants do not survive.²⁸ Assemblyman Kern's statement of purpose for Assembly Bill No. 963 expresses the problem:

Organ transplantation is now being extended to the very youngest patients, including newborns, but the shortage of donor organs is placing severe constraints on transplantation. Although the demand for infant organs is potentially large, the supply is virtually nil. Each year, according to one estimate, some 400 to 500 infants need new kidneys, while about 400 to 500 need hearts, and between 500 and 1,000 need livers.

Anencephalic infants are a potentially valuable source of human organs; it is estimated that about 3,500 such infants are born in this country each year. Although these infants constitute a potentially large supply of newborn organs, the laws of the various states do not currently permit these infants to be used as donors, even when their parents insist on such donation.²⁹

This reason is especially compelling to the parents of the anencephalic because they feel they can help alleviate the suffering of others.

between supply and demand is likely to grow greater in the years to come as transplantation techniques for infants are perfected

While infant donors have been found for some children with fatal congenital heart defects, there are very few such donors available. The pool of potential donors consists almost exclusively of those who have died as a result of child abuse, those born asphyxiated and who are, as a result, brain dead, or those children who suffer sudden infant death syndrome (SIDS) in a neonatal surgery.

Id. (citations omitted).

28. Harrison, *supra* note 19, at 1383, col. 1.

29. N.J. Bill A-963, 40th Leg., 202d Sess., (1988) (statement of purpose) (introduced pending technical review by the legislative counsel).

Further supporting anencephalic organ donation are scientifically oriented arguments: Anencephalic infants have an utterly hopeless prognosis.³⁰ They are permanently unconscious and terminally ill, and their diagnosis can be easily established both *in utero* and at birth with an extraordinarily high degree of certainty.³¹ Because these infants are permanently unconscious and can experience no pain or suffering, hence can never be aware of what happens to them, they have no interest in treatment, i.e., treatment can neither benefit nor harm them.³²

It is further argued that very little is known about the immune system of very young children, so the potential benefits from the research and development of transplant procedures in the young could further knowledge regarding all transplantation.³³ Moreover, the failure to pursue infant organ donation will mean that either transplantation will not be available to many infants and adults, or that researchers will be forced to rely on primates³⁴ (e.g. Baby Fae's heart from a baboon donor) as the source for transplantable organs.³⁵

The most widely contended argument against anencephalic organ donation³⁶ is the "slippery slope" scenario.

30. See *Crossing a Threshold*, *supra* note 8, at 193.

31. *Id.*

32. *Id.*

33. See Caplan, *supra* note 9, at 125.

34. See Fletcher, Robertson & Harrison, *Primates and Anencephalics as Sources for Pediatric Organ Transplants*, 1 *FETAL THERAPY* 150 (1986). Cross species transplants is properly referred to as a "xenograft." Xenograft has been defined as: n. [xeno + graft] A transplant from one species to another, sometimes used to indicate a wider genetic or species disparity than in a heterograft. *DORLAND'S ILLUSTRATED MEDICAL DICTIONARY* 1477 (26th ed. 1985).

35. See Caplan, *supra* note 9, at 127.

36. In addition to the reasons discussed in the text, a number of less convincing though defensible arguments have been presented. See Caplan, *supra* note 9, at 127. Organ donation from an anencephalic may encourage abortion since the enactment of laws permitting termination of life based upon brain absence might legitimize the destruction of fetuses prior to the time at which they possess brain activity. *Id.* at 135. Organ donation is extremely expensive, so the shortage of organs is a blessing rather than a burden. *Id.* at 139. By saving the money which would be required for one infant heart transplant, perhaps several others could benefit from the medical dollars spent. *Id.* at 139-40.

This argument contends that if organ removal is permitted from the anencephalic infant, undoubtedly the most vulnerable human being, then what is to stop the extension of this practice to the permanently comatose or those with other terminal conditions?³⁷ Furthermore, because of the tremendous need which exists for all organs, including child, adult, and infant, societal pressures may come to bear upon organ donation thus compelling an expansion of any existing legislation permitting anencephalic donation to further include other categories of incompetents.³⁸

Those who oppose anencephalic organ donation see a potential threat to the parents of the anencephalic infant.³⁹ Anencephaly is usually diagnosed *in utero*.⁴⁰ Opponents point out that societal pressures may come to bear upon the parents of the anencephalic thereby coercing them in to carrying an anencephalic fetus to term rather than pursuing the abortion

37. See *Symied*, *supra* note 12, at 10, col. 2.

38. See Arras & Shinnar, *Anencephalic Newborns as Organ Donors: A Critique*, 259 J. AM. MED. ASS'N 2284 (1988) [hereinafter Arras]. (Authors argue that current principles of the strict definition of brain death are sound public policy and good ethics and conclude that admirable goals should not be advanced by improper means. *Id.* at 2285).

39. See, e.g., Annas, *supra* note 21, at 38, col. 1.

40. Shewmon, *Anencephaly: Selected Medical Aspects*, HASTINGS CENTER REPORT, Oct.-Nov. 1988, at 11.

[Anencephaly] is, of course, drastically reduced in areas with active prenatal screening programs. Either ultrasound or maternal serum alphafetoprotein (MSAFP) measurements will identify nearly all anencephalic fetuses tested during the second trimester. Experience here, as in other countries with well-developed screening programs, indicates that the vast majority of detected anencephalic fetuses are electively aborted.

Id. at 12. See also Botkin, *supra*, note 12, at 251. "The greater use of maternal a-fetoprotein screening in the near future may have a substantial effect on the prevalence of anencephaly at delivery." *Id.* Large scale screening of pregnant women has been shown to have a sensitivity or 80% to 100% for the detection of anencephaly when combined with ultrasonography. *Id.* See also Thom, *The Impact of Maternal Serum Alpha fetoprotein Screening on Open Neural Tube Defect Births in North-East Scotland*, PRENATAL DIAGNOSIS, Jan. 1985, at 15; Milunsky, *Harvesting Organs for Transplantation From Dying Anencephalic Infants*, 82 PEDIATRICS, Aug. 1988, at 274, 275 (citation omitted); Chevernak, Isaacson & Mahoney, *Advances in the Diagnosis of Fetal Defects*, 315 N. ENGL. J. MED. 305 (1986).

option.⁴¹ They further argue that once a parent has been so coerced, if the fetus fails to survive to term, or otherwise fails to become a donor, then the parent's tragedy is compounded further.⁴²

Fundamentally, it is argued that anencephalic organ donation violates basic ethical precepts expounded upon by Immanuel Kant who wrote that humans are an end in themselves and therefore should never be used as merely a means to an end.⁴³ As "ends in themselves," Kant believed that persons have an intrinsic worth that cannot be reduced to their instrumental value to others.⁴⁴ "Act so as to treat humanity, whether in your own person, or in that of another, always as an end and never as a means only."⁴⁵ The question is whether prolonging the anencephalic infant's life by artificial life support and then extracting the vital organs is compatible with the minimum respect due to all persons.⁴⁶

Opponents, as well as some proponents are concerned

41. See Chevernak, Farley, Walters, Hobbins & Mahoney, *When is Termination of Pregnancy During the Third Trimester Morally Justifiable?*, 310 N. ENGL. J. MED. 501 (1983). Anencephaly is grounds for third trimester abortions and such procedures are performed in the United States. *Id.* at 501. The authors argue that such abortions are morally justifiable because first, the fetus is afflicted with a condition which is either incompatible with postnatal survival for more than a few weeks or characterized by the total or virtual absence of cognitive function, and second, highly reliable diagnostic procedures are available for prenatal determination. *Id.*

42. See Annas, *supra* note 20, at 38 col 1. The majority of anencephalic fetuses are stillborn. Their organs are not transplantable. *Id.*

43. See Arras, *supra* note 38, at 2284, col. 2.

44. *Id.* Kant's reasoning may be countered with this argument: if the anencephalic could (miraculously) reflect on his plight, he would consent to organ donation, because losing vital organs would not deprive him of anything he would desire. *Id.*

45. I. KANT, *Foundations of the Metaphysics of Morals* 47 (1785) (Lewis White Beck trans. 1959). See *Symied*, *supra* note 12, at 10, col 4: Dr. Tomasine Kushner, PhD. with the University of California at Berkeley, contends that organs should be taken from the anencephalic before primates because "[a]nencephalics do not have the same moral claim as any creature with cognitive awareness, be it a baboon or anything else." *Id.* This reasoning is based on the fact that anencephalic can never be self-aware individuals with a "biography." *Id.* Alexander Capron, professor of law, medicine and public policy at the University of Los Angeles argues by saying that "we have different duties to humans that we do to other species." *Id.* But see Redmon, *How Children Can Be Respected as "Ends" Yet Still Be Used as Subjects in Non-Therapeutic Research*, 12 J. MED. ETHICS 77 (1986).

46. See Arras, *supra* note 38, at 2284, col. 2.

that amending the laws on organ donation to include organs removed from anencephalic babies might undermine the public's support for and confidence in organ transplantation:

The prospect of taking organs or tissues from a human being who is breathing and performing other bodily functions without mechanical assistance would be repugnant to many both within and outside the medical community. Such activity, even if done with the full consent of parents, might totally undermine the public's faith and trust in organ procurement and those who engage in it.⁴⁷

While society overwhelmingly supports organ donation and transplantation,⁴⁸ this support and confidence could vanish if society perceived any abuse.

There is no easy answer to the ethical dilemma presented in shortening the anencephalic's life, no matter how short the life expectancy and no matter how absent its awareness. To many, the question can be decided by a balancing of the benefits approach. In balancing the detriment to the anencephalic who will live only a few days and live without any cognizance of its existence, against the benefit to the organ recipient (a full life expectancy), to the anencephalic's parents (beneficence mitigating the tragedy),

47. See Caplan, *supra* note 9, at 137.

48. See UNIF. ANATOMICAL GIFT ACT, 8A U.L.A. 2 (Supp. 1987).

PREFATORY NOTE

A 1985 Gallup Poll commissioned by the American Council on Transplantation reported that 93 percent of Americans surveyed knew about organ transplantation and, of these, 75 percent approved of the concept of organ donation. Although a large majority approves of organ donation, only 27 percent indicate that they would be very likely to donate their own organs, and only 17 percent have actually completed donor cards. Of those who were very likely to donate, nearly half have not told family members of their wish, even though family permission is usually requested before an organ is removed. (Report of the Task Force on Organ Transplantation pursuant to the 1984 National Organ Transplant Act-P. L. 98-507-*"Organ Transplantation: Issues and Recommendations"* (April, 1986)).

and to society (through advancement of medical procedures and understanding), proponents view the donation by the parents as acceptable even in light of the Kantian argument which squarely rejects the balancing approach.⁴⁹ There is clearly no tangible benefit to the anencephalic donor.⁵⁰ The benefit is for the recipient, the parents', and society.

II. THE LEGAL CONSIDERATIONS

A. *Consent and the Uniform Anatomical Gift Act*

Under the common law, no one could consent to the disposition or use of their body after death.⁵¹ The courts considered a corpse to be "res nullius" (no one's property) or "res extra commercio" (property that cannot be bought or sold).⁵² Later developments in the common law responded to the use of cadavers obtained principally from autopsied and unclaimed bodies which were needed for research and teaching.⁵³ In the mid-1950s the use of cadaver parts and organs became feasible for transplantation, but due to gaps in the common law, and varying and incomplete statutory provisions, hospitals and physicians found it extremely difficult

49. See Arras, *supra* note 38, at 2284, col. 2.

50. *But see* Arras, *supra* note 38, at 2284, col. 2.

One response to this objection is to claim that if the anencephalic infant could (miraculously) reflect on his plight, he would consent to organ donation, since losing vital organs would not deprive him of anything he would desire. Similar argument can be made using the social contract theory of Rawls, in which the decision maker is unbiased because he does not know what role (parent, recipient, anencephalic infant, or physician) he would have in the societal drama and therefore tries to minimize the worst outcome, which may be a person in need of an organ with no available donor.

Id.

51. See D. Myers, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING, §17:4, at 520 (1981) [hereinafter DEATH AND DYING] ("[p]art of the reluctance to recognize any property right in the dead body undoubtedly stemmed from fears that to do otherwise might encourage a scurrilous trade in dead body parts.") *Id.*

52. See *id.*

53. Cotton & Sandler, *Regulation of Organ Procurement and Transplantation*, 7 J. LEGAL MED. 55, 59 (1986).

to determine whether they could remove an organ without subjecting themselves to criminal and/or civil liability.⁵⁴ As a result of these difficulties, in 1968 the National Conference of Commissioners on Uniform State Laws (NCCUSL) formulated the Uniform Anatomical Gift Act (UAGA) which was adopted by all jurisdictions by 1972.⁵⁵

The UAGA sets forth who may make a gift of bodily parts for purposes of organ transplant.⁵⁶ Where the decedent has not, to the knowledge of the relatives, expressed a contrary intention, the surviving relatives, in the following order, may make a gift of the decedent's body parts: (1) spouse, (2) adult child, (3) parent, (4) adult brother or sister, (5) guardian of the person, (6) any other person authorized or under obligation to dispose of the dead body. Therefore, under the UAGA, if the anencephalic child is dead, the parents would be entitled to make the gift. A problem remains, however, in that the Uniform Determination of Death Act (UDDA) defines death as "[e]ither (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain stem," and that the determination of death be made in accordance with accepted medical standards.⁵⁷ As will be discussed, no accepted medical practices have been established which specifically pertain to anencephalia.

54. *Id.* at 59.

55. UNIF. ANATOMICAL GIFT ACT §§ 1-17, 8A U.L.A. 2 (Supp. 1987).

56. *Id.* at § 2, 8A U.L.A. 6 (Supp. 1987).

57. UNIF. DETERMINATION OF DEATH ACT, § 1, 12 U.L.A. 293 (Supp. 1989).

III. CONSENT OF MINORS (INCOMPETENTS) TO MEDICAL TREATMENT

Parental consent is required before performing medical treatment on minors or incompetents.⁵⁸ The President's Commission, in discussing medical care of the incompetent or minor wrote:⁵⁹

First, there is a presumption, strong but rebuttable, that parents are the appropriate decision-makers for their infants.⁶⁰ Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents.⁶¹

58. *Bowen v. American Hospital Ass'n.*, 476 U.S. 610 (1986) (in dicta the Court said, "[i]n broad outline, state law vests decisional responsibility in the parents in the first instance, subject to review in exceptional cases by the State acting as *parens patriae*." *Id.* at 627). See *Allen v. Roark*, 625 S.W.2d 411 (Tex. Ct. App. 1981) (Since an infant obviously is not able to evaluate information as to his condition or to consent to treatment, the privilege and right to receive and act upon that information belongs to the parents. *Id.* at 416); See also *Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941); *Ballard v. Anderson*, 4 Cal. 3d 873, 484 P.2d 1345, 95 Cal. Rptr. 1 (1971).

59. See LIFE SUSTAINING TREATMENT, *supra* note 7, at 212-13.

60. *Id.* at 212 n.62.

The common law antecedents of this presumption are largely to be found in a notion of paternal (and later parental) supremacy in family matters and in the corollary that children had few, if any, rights as persons, being regarded in law as chattels. These antecedents are now largely discredited and rejected, and have been supplanted by a tempered right of parental autonomy. This right has gradually developed under a constitutional aegis in this century, guided largely by principles of religious freedom and due process until the 1960s.

Id. (Footnote in original, author's note follows). See, e.g., *Meyer v. Nebraska*, 262 U.S. 390 (1923) (right to raise a child); *Prince v. Society of Sisters*, 268 U.S. 510 (1925) (parents' right to control education of their child); *Cf.*, *Prince v. Mass.*, 321 U.S. 158 (1944) (parental authority to have child [distribute] religious literature circumscribed). More recently, the theory began to be influenced by, and not assimilated to, the developing constitutional right of privacy. See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (parents' right to direct religious upbringing of children).

61. LIFE-SUSTAINING TREATMENT, *supra* note 7, at 212 n.63.

Familial privacy has received increasing protection from law throughout this century. In the earlier stages of legal development, the source of this protection was sometimes found in the constitutional right of religious freedom; it has gradually evolved into a more secular protection generally referred to as the right of privacy. The substantive core includes the

Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervene parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interest as to amount to neglect or abuse.

Plainly, these two legal doctrines - respect for parental discretion and protection of children against harm - pull in opposite directions and it is often difficult to know how to reconcile them in a particular case. These difficulties may partially account for the dispute over what constitutes "neglect and abuse." The meaning of these terms has varied over time and has rarely been the subject of careful legislative definition in statutes. Yet although the standards remain vague even in the medical arena, as long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervened.⁶²

authority of parents to establish family values, to set goals for the family and for its individual members, and to make decisions affecting the welfare of family members free from interference by agencies of the state. For example, although the law requires that children go to school, parents can generally choose the school. Parents must provide adequate food and shelter, but they need not conform to the opinions of others as to the best food or the most appealing shelter. The society as a whole benefits from promoting diversity, and privacy law has played an increasing role in protecting diverse life-styles and values.

Id.

62. LIFE-SUSTAINING TREATMENT, *supra* note 7, at 213 n.66.

Generally, when the medical treatment at issue for a minor child is for a disease or condition that is not severe or life-threatening, courts will accede to parental wishes not to treat even when physicians disagree. The courts have been particularly reluctant to order treatment when it is possible to delay the decision until the child reaches the age of majority. See, e.g., *In re Sieferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (surgery not ordered for 14-year-old boy with cleft palate); *In re Green*,

It is precisely this *parens patriae* power of the state that gives the opponents of anencephalic organ donation the power of the state to prevent the organ donation. Because the donation is not for the interests of the child, the extraction can be viewed, at least, as abuse and at worst, murder.

A. *Consent of Minor to Organ Removal*

Once transplantation became a medical possibility, the courts were presented with questions as to whether an organ could be removed from a living donor who was unable to consent because of incapacity or age.⁶³ While, as discussed above, the parents are the most suitable to make this decision, the primary consideration of the courts (in protecting the state's interest) has been whether the treatment is for the benefit of the child.⁶⁴ Although organ removal, even non-vital organ removal, can never, without more, be for the benefit of the donor, courts have upheld such donation where a

220 Pa. Super. Ct. 191, 286 A.2d 681 (1971) (surgery to correct spinal curvature). Likewise, even when the consequences of foregoing treatment may be grave, courts have refused to order treatment where parents have had well-grounded concerns that the risks outweigh the possible benefits. *In re Tuttendario*, 21 Pa. Dist. 561 (1912) (treatment for rickets may have been more dangerous than the disease). *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942) (surgery for greatly enlarged and useless arm with "gross possibility of fatality"). *But see, In re Sampson*, 29 N.Y.2d 900, 279 N.E.2d 918, 328 N.Y.S.2d 686 (1972) (over parental objection, court ordered surgery for 15-year-old boy with neurofibromatosis whom the court described as grotesque and repulsive), criticized in Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, WHO SPEAKS FOR THE CHILD 153, 180-84 (W. Gaylin & R. Macklin eds. 1982).

Id.

63. See DEATH AND DYING, *supra* note 51, § 6.1, at 99.

64. See *Bonner v. Moran*, 126 F.2d 121 (1941) The primary consideration in all cases considering medical treatment for minors without parental consent seems to be whether or not the treatment is for the benefit of the child, to preserve his life or health. *Id.* at 123. Skin grafts from child, without parental consent, were grounds for damages. *Id.* at 123. See also *Zaman v. Schultz*, 19 Pa. D. & C. 309 (1932) (blood tests and transfusions from minor without parental consent was grounds for damages to the parents).

"psychological benefit" would be gained.⁶⁵

B. Brain Death

Because modern technology has given doctors the ability to artificially maintain the heart and lung functions of the patient whose brain has become irreparably damaged, the traditional criterion for establishing death become less adequate.⁶⁶ In a highly influential publication, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death⁶⁷ stated:

[o]ur primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is need for a definition: (1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged . . . (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.⁶⁸

65. See *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. Ct. App. 1969) (parental petition for removal of one kidney from incompetent son for the benefit of his brother granted because of the psychological benefit to the incompetent); *Little v. Little*, 576 S.W.2d 493, 498 (Tex. Civ. App. 1979) (kidney removal permitted where the psychological benefit to the incompetent who enjoyed a dependent relationship with brother was sufficient to warrant the procedure).

66. See DEATH AND DYING, *supra* note 51, § 3:4, at 22.

67. Special Communication, Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 J. AM. MEDICAL ASS'N 85 (1968).

68. *Id.*

Brain death soon became the acceptable standard for determination.⁶⁹ By 1981, in a joint recommendation by the American Medical Association,⁷⁰ the American Bar Association, the National Conference of Commissioners on Uniform State Laws,⁷¹ most states,⁷² and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research⁷³ have endorsed the

69. See *Defining Death*, *supra* note 2, at 162-63.

The Criteria for Determination of [Brain] Death:

1. CESSATION IS RECOGNIZED WHEN EVALUATION DISCLOSES FINDINGS OF a AND b:

a. CEREBRAL FUNCTIONS ARE ABSENT, AND . . .

There must be a deep coma, that is, cerebral unreceptivity and unresponsivity. Medical circumstances may require the use of confirmatory studies such as EEG or blood flow study.

b. BRAINSTEM FUNCTIONS ARE ABSENT.

Reliable testing of brainstem reflexes requires a perceptive and experienced Physician using adequate stimuli. Pupillary light, corneal, oculocephalic, oculovestibular, oropharyngeal, and respiratory (apnea) reflexes should be tested. When these reflexes cannot be adequately assessed, confirmatory tests are recommended.

Adequate testing for apnea is very important. An accepted method is ventilation with pure oxygen or an oxygen and carbon dioxide mixture for ten minutes before withdrawal of the ventilator, followed by passive flow of oxygen. (This procedure allows PaCO₂ to rise without hazardous hypoxia.) Hypercarbia adequately stimulates respiratory effort within thirty seconds with PaCO₂ is greater the 60 mmHg. A ten minute period of apnea is usually sufficient to attain the level of hypercarbia. Testing of arterial blood gases can be used to confirm this level. Spontaneous breathing efforts indicate that part of the brainstem is functioning.

Peripheral nervous system activity and spinal cord reflexes may persist after death. True decerebrate or decorticate posturing or seizures are inconsistent with the diagnosis of death.

Id.

70. See *Guidelines for the Determination of Death*, 246 J. AM. MED. ASS'N 2184, 2186 (1981).

71. The UNIF. BRAIN DEATH ACT (UBDA), 12 U.L.A. 16 (Supp. 1989), was adopted in 1978 and is currently enacted in only two states, Alabama and West Virginia. However, this Act was superseded in 1980 by the UNIF. DETERMINATION OF DEATH ACT (UDDA), 12 U.L.A. 312 (Supp. 1989).

72. THE UNIF. DETERMINATION OF DEATH ACT (UDDA), 12 U.L.A. 312 (Supp. 1989), has been adopted in 24 jurisdictions: Arkansas, California, Colorado, Delaware, District of Columbia, Georgia, Idaho, Indiana, Kansas, Maine, Maryland, Mississippi, Missouri, Montana, Nevada, New Hampshire, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Vermont and Wyoming.

73. See *Defining Death*, *supra* note 2, at 160.

following language which has been codified in the UDDA:⁷⁴ An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions or (2) irreversible cessation of all functions of the entire brain, including the brainstem, is dead. A determination of death must be made in accordance with accepted medical standards.⁷⁵

IV. THE DIFFICULTY DETERMINING BRAIN DEATH IN CHILDREN AND INFANTS

Pronouncement of brain death in children is especially difficult.⁷⁶ A Presidential Commission established to study "the ethical and legal implications of the matter of defining death"⁷⁷ described the problem: "The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods than do adults. Physicians should be particularly cautious in applying neurologic criteria to determine death in children younger than five years."⁷⁸

In an effort to establish "brain death" criteria for younger children, a Special Task Force was convened to

74. UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 312 (Supp. 1989).

75. UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 312 (Supp. 1989). West Virginia has omitted "including the brain stem." UNIF. BRAIN DEATH ACT § 1, 12 U.L.A. 17 (Supp. 1989). Therefore, in West Virginia, an anencephalic could be considered "dead" at least for purposes of organ transplantation. *Id.*

76. See Caplan, *supra* note 9, at 121; see also Annas, *supra* note 21 at 37; Volpe, *Commentary; Brain Death Determination in the Newborn*, 80 PEDIATRICS, Aug. 1987, at 293.

77. See *Defining Death*, *supra* note 2, at 1. See also 42 U.S.C. § 1802 (1978) (enabling legislation).

78. Special Communication, Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Guidelines for the Determination of Death*, 246 J. AM. MED. ASS'N 2184, 2186 (1981). See *Defining Death*, *supra* note 2, at 166.

establish acceptable criteria for brain death in children.⁷⁹ The criteria, however, are inapplicable to children less than one week old.⁸⁰ Further exacerbating the problem is that the process of dying adversely affects the tissue in a child more than it does in an adult. Therefore, by the time a determination of death by cessation of cardiorespiratory functions occurs, an infant's organs would no longer be suitable for transplantation.⁸¹

A. *The Brain-Death Standard and the Anencephalic*

Many commentators question whether a brain death standard is even applicable to the anencephalic because of the absence of a brain.⁸² It is argued that new criteria should be established for the determination of death as to anencephalics, such as when the body's major organ system stops functioning in an organized fashion.⁸³ Noted ethicist Dr. Caplan said "I am unwilling to have public policy that does not let anyone under seven days die. With anencephalics, you can't insist on measuring [the brain's] function because the [brain] isn't there."⁸⁴

Others consider whether there is any moral significance to the UDDA's requirement of "irreversible cessation of . . . the brainstem."⁸⁵ They reason that anencephalic newborns have been selected as possible donors because they lack higher brain structures and the condition is uniformly fatal

79. See Task Force on Brain Death Determination in Children, *Guidelines for the Determination of Brain Death in Children*, 80 PEDIATRICS, Aug. 1987, at 298. The Task Force reported "[t]here are no unique legal issues in determining brain death in children as compared with adults. The unique issues are all medical ones and related directly to the more difficult tasks of confirming brain death in young children." *Id.*

80. *Id.*

81. See *Death Unto Life supra* note 21 at 1536. "Without . . . cardiopulmonary function, the anencephalic infant's organs lose viability" *Id.*

82. See *Symied, supra* note 12, at 10, col. 4.

83. *Id.*

84. *Id.*

85. See Botkin, *supra*, note 12, at 252.

within a short period of time.⁸⁶ The question becomes what is the moral significance of whole brain death versus the absence of higher brain function? (i.e. What is the significance afforded to brainstem activity?)⁸⁷ The answer given is:

Brainstem activity alone provides a meager existence. Loss of higher brain functions robs us of all that makes us human in any sense beyond that defined by our genetic endowment.

* * *

Based on any criteria that require some level of cognitive function, an argument could be made that brainstem activity alone has no intrinsic moral significance. Individuals who have permanently lost higher brain function have ended their lives in a biographical sense and are no longer persons to whom we have duties of life sustaining support. Any significance afforded to brainstem activity would be that created by prognostic uncertainty. There are those rare cases in which miraculous recovery occurs despite apparent loss of all higher brain activity. The anencephalic infant, of course, has no prospect for recovery. Thus, the brainstem activity in these infants has no significance, . . . and these infants are therefore indistinguishable from brain-dead individuals.⁸⁸

B. Murder

Because of these difficulties, any gift of the living anencephalic's organs would at the very least hasten the child's

86. *Id.*

87. *Id.*

88. *Id.*

death,⁸⁹ and at worst the donation would be the proximate cause of death,⁹⁰ breaking the causal chain of anencephaly.⁹¹

While organ removal from an anencephalic technically is murder, no such cases have been reported.⁹²

Proximate cause arguments, which frequently arise in criminal cases,⁹³ can form the basis for a policy permitting vital organ removal without imposing criminal liability on the organ removal team.⁹⁴ Proximate cause arguments occur in murder trials where defendants have maintained that the victim of their act was still alive when either the artificial life supports were turned off or organs were removed.⁹⁵ In discussing the proximate cause theory, the President's

89. Annas, *supra* note 21, at 36. Most involved with the anencephalic issue believe that anencephalics are living human beings and that removal of their organs would kill them and be murder. *Id.* See Landwirth, *supra* note 20, at 258 ("[in the view of some,] transplantation of vital organs from living anencephalic newborns would be both immoral and illegal." *Id.*). See also *Crossing A Threshold*, *supra* note 18, at 194.

90. See *Committee Report*, *supra* note 4, at 364, col. 1. See also *CROSSING A THRESHOLD*, *supra* note 18, at 194.

91. See *Crossing a Threshold*, *supra* note 18, at 194.

Furthermore, removing vital organs such as heart, lungs, liver, or both kidneys from anencephalic infants is the proximate cause of death - even though these infants are permanently unconscious and truly dying . . . There is no medical-moral consensus concerning the morality of using anencephalics as organ donors, but the traditional case and statutory law seems clear - such an action would currently be construed as homicide . . . But the fact remains that by any reasonable interpretation, removing vital organs from living persons - even those who are permanently unconscious and dying - can only be construed as directly causing death.

Id.

92. *Id.* ("It may be that, as we begin to develop a consensus, and as these cases are challenged in court, judges and juries will find this is a form of justifiable homicide or, if anencephalic infants are classified as dead or in some other category of neither alive or dead, it will not be possible to kill something that is already dead, or not living, or not a person." *Id.*).

93. See *Johnson v. State*, 64 Fla. 321, 59 So. 894 (1912); *Hamblin v. State*, 81 Neb. 148, 115 N.W. 850 (1908).

94. *Defining Death*, *supra* note 2, at 136.

95. *DEATH AND DYING*, *supra* note 51, § 17:12, at 533-35 (citing *People v. Lyons*, No. 56072 (Cal. Super. Ct., Alameda Co. 1974); *When Do We Die?*, 4 MED. SCI. L. 59 (1964) (discussing *Regina v. Potter* (Ct. Crim. App. 1963), an unreported English case)).

Commission wrote:⁹⁶

The proximate cause argument relies upon the well accepted legal principle that a criminal defendant is liable for the natural consequences of his act.⁹⁷ Even negligent care by physicians attending the victim of an alleged criminal act does not relieve the defendant from the responsibility for the consequences. Thus, even if the defendants in these cases were correct that their victims had still been legally alive when artificial respiratory support systems were removed, their indictments and convictions would not thereby be invalid. "The state is only required to prove beyond a reasonable doubt that the defendant's acts were a substantial factor in producing the death."⁹⁸

While organ removal from an anencephalic accelerates the actual time of death, anencephaly can still be logically construed as the proximate cause of the death. Nevertheless, the question is still open.

V. SOLUTIONS

Because there is no clear direction as to legality, proponents very cautiously move forward. They do so by creating a protocol for dealing with the anencephalic newborn which they believe comports as closely as possible with acceptable practices.

96. *Defining Death*, *supra* note 2, at 136.

97. *Id.* at 136 n.5 (citing *Johnson v. State*, 64 Fla. 321, 59 So. 894 (1912); *Hamblin v. State*, 81 Neb. 148, 115 N.W. 850 (1908)). Thus, only an independent intervening cause of the ultimate harm can absolve the defendant of guilt. *See State v. Smith*, 496 So.2d 195, 196 (Fla. Dist. Ct. App. 1986).

98. *Id.* at 136 n.6 (citing *Cranmore v. State*, 271 N.W.2d 402, 428 (Wis. App. 1978)).

A. Canadian Protocol

The Canadian team which made the decision to allow the donation of Baby Gabrielle's organs established a protocol which required the parents to agree, prior to birth, that: (1) the infant will be resuscitated;⁹⁹ (2) periodic testing will be done to determine brain death¹⁰⁰ (removal from the ventilator at six to twelve hours intervals for a ten minute period to determine ability to breathe spontaneously); (3) organ donation is acceptable;¹⁰¹ and (4) a definite time limit (to be determined by the parents but not more than fourteen days) after which the infant will be removed from the ventilator and permitted to die.¹⁰²

B. The Loma Linda University's Protocol

In 1986 Loma Linda University Medical Center (LLUMC) considered a parental request to accept a dying anencephalic newborn as an organ donor so that another baby might live.¹⁰³ The group declined concluding that the organ procurement would be illegal because it would be utilized before brain death was determined.¹⁰⁴ The committee formed to consider the possible use of anencephalic infants as organ sources, consisted of specialists in neonatology, pediatric surgery, ethics, child neurology, nursing, administration, and

99. Resuscitation is aggressive life sustaining treatment. See LIFE-SUSTAINING TREATMENT, *supra* note 7, at 181-86. This form of treatment is not normally given to the anencephalic infant for fear that if the treatment gives sufficient strength to the brainstem, the child might live for a prolonged period. *Id.* It is widely agreed that to forego such treatment is the proper course of treatment. *Id.* (discusses the "balancing test" necessary in continuing treatment for the permanently unconscious patient).

100. One critic claimed that putting Baby Gabrielle on a respirator and feeding her intravenously rendered the protocol "an elaborate little shell game" used to get around the ethical difficulties. *Baby Without Brain Kept Alive to Give Heart*, *supra* note 21, at B9, col. 2.

101. See Annas, *supra* note 21, at 37.

102. *Id.*

103. See Walters, *supra* note 10, at 22, col. 2 (insert).

104. *Id.*

law.¹⁰⁵ The committee produced three drafts of a protocol for limited respirator use to sustain anencephalic infants until brain death could be determined.¹⁰⁶ However, the protocol was temporarily tabled for lack of a good answer to the pivotal question: What assurance is there that an anencephalic infant attached to a respirator will predictably die within a reasonable amount of time?¹⁰⁷ Commentators stated that "all discussants showed reticence to contemplate research on these weakest of human beings."¹⁰⁸ On December 18, 1987, the Medical Center's determination was reported in *The Modified Medical Management of Anencephalic Infants for Organ Donation*.¹⁰⁹

At the request of anencephalic infants' parents and after extensive consideration, Loma University Medical Center has adopted a modified protocol of medical management that may provide an opportunity for these infants to meet organ donation criteria

After the diagnosis of anencephaly is confirmed, the parents should have the opportunity to decide whether they wish to donate their infant's organs. If the parents have made a firm statement that they wish to donate their infant's organs and have signed consent for the modified medical management protocol, the infant will be intubated . . . at birth and supported with mechanical ventilation Support to maintain organ viability will be continued for a preset period of time . . . [We] recommend that a limit to the duration of

105. *Id.*

106. *Id.*

107. *Id.*

108. *Id.*

109. *Id.* at 23, col. 1.

intensive care be set prior to the initiation of mechanical ventilation and that it not exceed one week.

Examinations for determination of brain death should be carried out twice daily by a qualified physician. Brain death must be confirmed by two physicians free from conflict of interest [e.g. they should not be involved in the direct care of a potential organ recipient]. If brain death is confirmed, the infant may then be considered for organ donation. The same protocol that is used for all organs donations should be followed for anencephalic infants meeting brain death criteria A separate consent should be obtained from the family for organ donation. The consent should be organ and institution specific

If brain death criteria are not met within the preset time for intensive care, mechanical ventilation should be stopped, the infant extubated, and customary comfort care practices should be followed, up to the time of death.¹¹⁰

Modification of Protocol (April 15, 1988):

Upon evaluation of experience with the original protocol, it is obvious that provision of full intensive care from birth alters the natural course of dying, resulting in prolongation of the dying process. The protocol is henceforth modified for the next six infants in the following manner: a) the newborns are not to be placed on respirator support at birth, but only after cardiac-respiratory failure occurs suggesting imminent death; b) if brain death has not been

110. *Id.*

determined after intensive support for twenty-four hours, mechanical ventilation is withdrawn and death is allowed to occur without further intervention; c) if brain death criteria are met within the twenty-four hours, intensive care is continued and a confirmation of brain death by an outside neurologist referee would be sought, allowing an additional twelve to twenty-four hours. The infant then is registered as a potential donor with procurement agencies.¹¹¹

C. Transplantation Policy Center; Michigan

In 1986 the state of Michigan established the Transplant Policy Center to conduct research and examine issues relevant to the formulation of sound public policy on transplantation.¹¹² The committee taking up the issue of anencephalic organ donation is comprised of two transplant surgeons, two transplant coordinators, a transplant social worker, a nephrologist, an epidemiologist, a neonatologist, a psychiatrist, a nurse educator, a health policy planner, a transplant recipient, two philosophers, and two members of the clergy.¹¹³ In a full report, the Committee analyzed the three major positions:

(1) that the removal of transplantable organs from anencephalic infants is impermissible because they are living human beings, and attempting to preserve their organs until they are brain dead treats them as mere means; (2) that the removal of transplantable organs from

111. *Id.*

112. Ethics and Social Impact Committee, Transplant Policy Center, *Anencephalic Infants as Sources of Transplantable Organs*, HASTINGS CENTER REPORT, Oct.-Nov. 1988, at 28.

113. *Id.*

anencephalic infants is permissible because under a revised conception of death - one that would identify death with total and permanent loss of consciousness - all such infants are dead; and (3) that infants born with the top half of their brains missing are so very different from other living infants - and their future so radically limited - that it is permissible, with the fully informed and freely given consent of the parents, to remove their organs for transplantation.¹¹⁴

The Committee endorsed the third and stated their Policy Recommendations:

Anencephalic infants are suitable organ donors without delay, whatever else may be true about their status.

The philosophical position . . . we adopt does not reconcile the two above, nor does it seek to resolve the underlying dilemma presented by alternative conceptions of brain death . . . Hence we cannot say with confidence whether anencephalic infants should be thought of as alive or dead.

We are confident, nevertheless, that as a moral matter, it is right to transplant the organs of such infants to save lives that can be saved only in that way, and we believe that it is wrong to refrain from doing so, if the fully informed consent of the parents has been given. We defend not an *intermediate* position in the conflict recounted above, but a position that *bypasses* that conflict.

The third position holds that anencephaly is a condition so special, so very different from

114. *Id.*

all others, and one whose diagnosis and prognosis can be established with such manifest certainty, that infants in this most unfortunate condition should be viewed as in a class that is entirely *sui generis* and one for which special rules and laws should apply.¹¹⁵

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While this Committee's report is not "law," presumably it will become the basis for legislation in the state of Michigan.

D. England: Redefinition of Death

In the United Kingdom, a Working Party of the Medical Royal Colleges has redefined the determination of death for the anencephalic infant.¹¹⁶

They concluded that organs could be removed from an anencephalic infant after two physicians (not members of the transplant team) "agreed that spontaneous respiration has ceased." They held that while brainstem function tests are used in adults to determine brain death, such tests are "inapplicable when the forebrain itself is missing." Hence, logically, they maintained that, if, in the adult, brain death plus apnea¹¹⁷ is recognized as death, by analogy, "the absence of the forebrain in these infants plus apnea would similarly be recognized as death." This would allow

115. *Id.* (emphasis in original text).

116. Milunsky, *Harvesting Organs for Transplantation from Dying Anencephalic Infants*, 82 PEDIATRICS 274, 275 (1988) [hereinafter Milunsky] (citing Conference of Medical Royal Colleges and their Faculties in the UK, Report of a Working Party on Organ Transplantation in Neonates (Department of Health and Social Security, 1988)).

117. Apnea, Apnoea: n. [a-+pnea]. The cessation or suspension of breathing. STEDMAN'S MEDICAL DICTIONARY 97 (24th ed. 1982).

harvesting of organs from anencephalic infants who may exhibit eye movements, pupillary response to light, spontaneous or induced movements of the face, limbs, or digits, including reflex swallowing, and whose corneal, gag, cough, sucking and rooting reflexes may be present.¹¹⁸

E. Germany: Anencephalics are Never Alive

In the Federal Republic of Germany, the courts accept the concept that the anencephalic fetus has never been alive despite the presence of a heartbeat¹¹⁹ and allow termination of pregnancy involving an anencephalic fetus at any time during gestation.¹²⁰ The German investigators responding to the need for infant organs adopted the court's policy, and in response to criticisms¹²¹ said: "[b]ecause rapid deterioration of vital signs makes most anencephalic infants unsuitable as donors after death . . . we believe that there are unfortunately no alternatives at present to intubating, immediately after birth, the anencephalic infant whose parents request kidney donation, until the kidneys have been removed."¹²²

VI. LEGISLATION

118. Milunsky, *supra* note 116, at 275.

119. Holzgreve, *Kidney Transplantation from Anencephalic Donors*, 317 N. ENGL. J. MED. 960 (1987).

120. *Id.* at 960-61.

121. See Letter from Rev. K. O'Rourke, *Kidney Transplantation from Anencephalic Donors*, 317 N. ENGL. J. MED. 960 (1987) (The German position that anencephalic infants may be considered brain dead or that the anencephalic fetus, because of the absence of brain development, has never been alive is strongly criticized because, the writer argues, "no organs should be removed until death has been certified on the basis of clinical signs." *Id.* at 961).

122. Holzgreve, *supra* note 119, at 961 (reply to Rev. O'Rourke's letter to the editor, see *supra* note 121).

In the United States, California and New Jersey are involved in legislatively resolving the problem.¹²³ Legislation is difficult because not only is it in derogation of the common law but statutory expansions of the common law adopted in all jurisdictions have already been made. Clearly any further expansion must be very narrowly tailored to the need otherwise the "slippery slope" could become a reality.

A. California

123. A narrowly drawn exception to the Uniform Determination of Death Act's whole brain death standard has recently been proposed by Andrea Scott, *Death Unto Life, supra* note 21, at 1565-66:

This amendment, crafted to exempt anencephalic infants from the current whole-brain death standard of the UDDA, embodies a policy decision about how best to maintain a supply of viable infant organs. The amendment would encourage organ donation by providing legal protection for physicians acting to preserve the lives of potential organ recipients. Protocols approved by institutional review boards should be used to provide both procedural safeguards and limited discretion to physicians acting in accordance with the amendment.

Id. at 1566.

DEFINING DEATH IN ANENCEPHALIC INFANT ORGAN DONORS

An anencephalic infant whose organs are to be used for transplantation may be declared dead at birth, whether delivered pre-term or full term as a result of spontaneous labor or cesarian section, if the following conditions are met:

(A) Prenatal Diagnosis of Anencephaly

(1) Prenatal diagnosis of anencephaly must be confirmed to a reasonable medical certainty by no less than three types of diagnostic testing, including but not limited to sonography, alpha-fetoprotein testing, and roentgenography.

(2) Prenatal testing must be performed by no less than three qualified physicians, including but not limited to an ultrasonographer, a perinatologist and a geneticist. All physicians performing such testing must be free from any involvement with all transplantation efforts and potential organ recipients.

(B) Neonatal Diagnosis of Anencephaly - Neonatal diagnosis of anencephaly must be confirmed to a reasonable medical certainty by no less than three qualified physicians, including but not limited to a neonatologist, a neurologist, and a geneticist. All physicians making the diagnosis must be free from any involvement with all transplantation efforts and potential organ recipients.

(C) Consent - Written and informed consent, reflecting a reasonable comprehension of the meaning and consequences of donation of the body of an anencephalic infant for organ donation, must be obtained from the parents of any anencephalic whose organs are to be used for transplantation.

Id. at 1565-66 (citations omitted)

California Senator Milton Marks introduced Senate Bill 2018 in February 1986¹²⁴ in a direct attempt to solve the problem. In its original form, the bill provided:

Existing law known as the Uniform Determination of Death Act provides that an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. This act also provides the manner for pronouncement of death, confirmation of death of a donor for an anatomical gift, and the keeping of medical records.

This bill would revise this definition to additionally provide that an individual born with the condition of anencephaly, as defined, is dead.¹²⁵

* * *

"Anencephaly", as used in this chapter, means markedly defective development of the brain, together with absence of the bones for the cranial vault and the cerebral and cerebellar hemispheres, and with only a rudimentary brain stem and some traces for basal ganglia present.¹²⁶

This bill has been substantially altered so that now a State Maternal, Child, and Adolescent Health Board would be established to study the anencephalic issue along with other related issues:

124. S. 2018, 1985-86 Leg., 1986 Sess., (Cal. 1986) (subsequently revised and under consideration).

125. *Id.*

126. *Id.*

[t]o review policies and develop recommendation, as specified relating to the care and treatment of infants born with life-threatening illnesses, conditions, or genetic defects.¹²⁷

The recommendations made . . . shall include the feasibility and necessity of infant organ transplants, the donation of organs from infants born with anencephaly and any necessary changes in the Uniform Anatomical Gift Act.¹²⁸

While this revised version of the bill does not directly solve the problem, it does have the benefit of affording a greater degree of due process to the issue. When an issue is as sensitive a matter of public policy as this is, this revised approach may in fact be best. If the benefits of anencephalic organ donation are determined to outweigh the inherent dangers, then society can step forward with open eyes into the situation it has created.

A further improvement in the revision is that the Act now requests that the State Maternal, Child, and Adolescent Health Board consider amending the UAGA rather than amending the UDDA. While the end result in either case is the same, the problem is that to declare a living, breathing baby as "dead" under the law defies logic and common sense, thus could undermine the public confidence in both the legislature and health care professionals.¹²⁹ By amending the UAGA, the benefit lies in bypassing that problem by simply declaring that the anencephalic infant is suitable for status as an organ donor.

127. *Id.*

128. *Id.*

129. See *supra* note 44 and accompanying text.

B. New Jersey Assembly Bill No. 963

Assemblyman Kern's proposal¹³⁰ is a direct solution to the anencephalic organ donor problem. The Bill permits parental consent for the donation prior to the determination of brain death by requiring a written request provided that neither parent objects.¹³¹

A parent of an anencephalic infant, either prior to or upon the birth of that infant, may submit to the attending physician or surgeon a written request for the donation of the body of that infant, or a part thereof, to any of the donees for any of the purposes stated in section 3 of the "Uniform Anatomical Gift Act"; to which the attending physician or surgeon shall consent in writing if the requested donation is medically suitable of purpose and safety, and if one of the parents does not object to the donation, regardless of whether the infant has sustained an irreversible cessation of circulatory and respiratory function or an irreversible cessation of all functions of the brain stem.

"Anencephalic infant" means a newborn infant who, as certified in writing by an attending physician or surgeon, has no skull above the forehead and no cerebral cortex, and is, therefore, considered to be "brain absent," which condition is always fatal and causes the infant to begin to die the moment that it is born."¹³²

The benefit of Assemblyman Kern's proposal lies in its

130. N.J. Bill A-963, 40th Leg., 202d Sess., (1988) (introduced pending technical review by the legislative counsel.).

131. *Id.*

132. *Id.*

expeditious resolution of the dilemma. The benefit, however, is at the expense of the due process concerns which are so well advanced in the California proposal. Thus, the New Jersey bill risks a public backlash. Such a response is unlikely though, as the benefits are obvious whereas the detriments are latent.

VII. CONCLUSION

This note's ghoulish title is not an entirely inaccurate account of the anencephalic's existence. The title is intended, in part, to give pause to consider a fundamental question which underlies this dilemma: What does it mean to be a person? Is it merely being the of human biology, or, is it something more? Must it include sentience, or, must it include the full compliment of a human biology, sentience, and sapience? Kantians answer this question easily and declare that society owes every duty to the anencephalic as it owes everyone else.¹³³ To others, however, the anencephalic's "brain-absence,"¹³⁴ renders its existence meaningless, because, without "personhood"¹³⁵ and, without an ability to form a "biography,"¹³⁶ life has no *raison d'être* and therefore, society does not owe the same duties to the anencephalic as it owes to everyone else.

From the above account, we can see that a consensus is beginning to form which would permit anencephalic organ donation. It is hoped that the medical profession will lead the way as the law should follow the reasonable standards of

133. See notes 41-43 *supra* and accompanying text.

134. See Harrison, *supra* note 19, at 1383. See also Arras, *supra* note 38, at 2284.

135. See Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, HASTINGS CENTER REPORT, Nov. 1972, at 1 (the author suggests, for purposes of biomedical ethics, fifteen positive propositions and five negative propositions which may explicate humanness or humaneness, what it means to be a truly human being); see also Szymied, *supra* note 12, at 10, col. 4; Arras, *supra* note 38, at 112.

136. See Szymied, *supra* note 12, at 10, col 4.

medical practice.¹³⁷ If, ultimately, such organ donation is determined acceptable by the medical profession, then the most direct next step is contained in Assemblyman Kern's proposal. Because medical technology has progressed far enough to give hope to the infant in need of an organ and because medical technology has not progressed far enough to give any hope to the anencephalic infant, the New Jersey and California Bills are appropriate legislation. To deprive the hopeful child of this opportunity will only assure that there will be two dead children. One living child is far better than two children dead. These Bills save lives.

Charles N. Rock

137. See *Crossing a Threshold*, supra note 18, at 196.