Anencephalic Infants as Organ Donors: A Question of Life or Death

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ANENCEPHALIC INFANTS AS ORGAN DONORS: A QUESTION OF LIFE OR DEATH*

The prospect of a larger supply of organ donors is positive in the abstract. But when the source of organs is anencephalic infants, a number of medical, ethical and legal concerns arise. The Author proposes that ventilator programs, provided that they follow certain ethical guidelines, are the best solution to the current debate. These programs balance the urgent need for organ donors with society's broader interest in respect for human life.

FROM THE MINUTE she was born, Baby Gabriel — named for the archangel who guards the gates of heaven — was dying.1 She suffered from anencephaly, a fatal congenital defect in which most of the brain is missing, except for a small portion of the brainstem. The brainstem of an anencephalic infant often sustains respiration so that vital organs function for a short time.2

Baby Gabriel's parents did not discover her condition until the eighth month of pregnancy, when the mother was prompted to have an ultrasound because the fetus had stopped kicking.3 Early in the pregnancy, the parents declined testing that could have detected the defect.4 Once the abnormality was discovered, Baby Gabriel's parents were given three options: induction of labor, Caesarean section, or carrying the fetus to term. They decided to continue the pregnancy and deliver their baby by natural childbirth.5 They also approached physicians about offering their infant's organs for donation.6

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2. See Fletcher, Robertson & Harrison, Primates and Anencephalics as Sources for Pediatric Organ Transplants, 1 Fetal Therapy 150 (1986) [hereinafter Sources]. See infra text accompanying notes 23-27.
4. Id.
5. Id.
Baby Gabriel was born on Monday, October 12, 1987 at Soldier's Hospital in Orillia, Ontario. She breathed on her own through the first night. The next day, she was transferred to Children's Hospital in Western Ontario and placed on a ventilator. Meanwhile, a recipient for Baby Gabriel's heart was found at Loma Linda University Medical Center (Loma Linda) in Los Angeles. Dr. Leonard L. Bailey was treating a patient who in a few weeks was due to deliver a fetus with hypoplastic left heart syndrome, a fatal disease in which the heart's left chamber is missing or atrophied.

Late Wednesday afternoon, physicians determined that Baby Gabriel could no longer breathe on her own and that she met the legal criteria for brain death. She was flown immediately to Loma Linda, where her death was confirmed. That Friday, Baby Gabriel's heart was transplanted into Paul Holc, who was delivered three hours earlier by Caesarean section. This was the first successful heart transplant from an anencephalic infant. Through his first year, Paul was a healthy, active child.

Baby Gabriel's story of tragedy and redemption has broad medical, ethical, and legal implications. Parents of anencephalic infants throughout the United States have expressed the same desire as Baby Gabriel's parents: that their child's organs be donated to bring life and health to other children. However, controversy has blocked further development of anencephalic organ

7. Id.
8. Annas, supra note 3, at 36.
9. Id.
10. Id.
11. Dr. Bailey is widely recognized for his pioneering work in infant heart transplants. In 1984 he transplanted a baboon heart into a 12-day-old girl, who survived 20 days. Baby is Awake and Moving After Transplant, N.Y. Times, Oct. 18, 1987, at 34, col. 4 [hereinafter Baby is Awake].
12. Id.
13. Annas, supra note 3. Some commentators have questioned whether Baby Gabriel's death was properly determined. See infra note 159 and accompanying text.
15. Baby is Awake, supra note 11, at 34, col. 4.
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donation in the United States. This Note analyzes the various approaches to obtaining organs from anencephalic infants, focusing on such fundamental issues as defining death and using one human being for the sake of another.

In Part I, this Note explains why anencephalic infants may create an excellent source of pediatric organs, and why the need for these organs is urgent. Part I also outlines the underlying controversy concerning the definition of death. Part II discusses the proposed methods of anencephalic organ donation. Part III examines the legal, ethical, medical and policy objections to these methods. Part IV explores the interests of all parties involved in the debate — the infant, the parents, and society — and develops the arguments that support or undermine such interests.

Part V concludes that preserving respect for human life outweighs the unknown benefits of anencephalic organ donation. Instead of allowing these infants to be killed so their organs can be used for transplants, procedures should be developed to preserve the organs until the infants meet the established criteria for death. This Note sets forth several safeguards to ensure that these programs are ethically sound. If these programs prove unsuccessful, this Note proposes that the data they generate be used to reconsider other approaches to obtaining organs from anencephalic infants.

I. THE PROMISE AND PERIL OF ANENCEPHALIC ORGAN DONATION

Cases such as Baby Gabriel's have stirred great controversy. The argument advanced by parents of anencephalic infants and echoed by many physicians, is both lofty and logical: anencephalic infants could be an invaluable source of organs at a time when the ability to transplant pediatric organs far exceeds the supply of organs. The major obstacle to anencephalic organ donation, however, is formidable. These donations challenge an ancient and fundamental concept already in transition: the definition of death.

A. The Anencephalic Infant as Organ Donor

Anencephaly is a congenital absence of skull, scalp and fore-
brain, or cerebral hemispheres. The cause is generally unknown, but is thought to operate very early in gestation. There are two types of anencephaly. In one, the skull and brain do not form above the brainstem; in the other, the skull and brainstem are present but the brain is not. Despite this devastating anomaly, the newborn's brainstem — itself often seriously malformed — may sustain its vital organs for a short time. The vital organs are intact and usually of high quality. The brainstem also regulates involuntary reflexes such as yawning, sucking, swallowing and facial grimaces. But because the babies lack any higher brain function, they generally are assumed to have no consciousness or awareness.

Anencephalic infants have been called "the most promising source of pediatric organs." They have been singled out primarily because the infants often have healthy vital organs, yet they meet a certain and swift death. Anencephaly is always fatal; there is no treatment. The only course of intervention is abortion. At least ninety-five percent of anencephalics die within their first week of life; only forty percent survive longer than twenty-four hours. Anencephaly is one of few conditions for which third-trimester abortions are permitted in the United States.

22. Id.
23. Caplan, Should Foetuses or Infants be Utilized as Organ Donors?, BIOETHICS, Apr. 1987, at 119, 123.
24. Shewmon, supra note 21, at 15 (the longest survival on record is fourteen months).
25. Sources, supra note 2, at 155.
27. Id. at 15.
28. Sources, supra note 2, at 151.
29. Walters & Ashwal, supra note 16, at 21; see also Botkin, Anencephalic Infants as Organ Donors, 82 PEDIATRICS 250, 253 (1988) ("The difference does not lie in the level of neurological function but in the length of life to be sacrificed.").
31. Baird & Sadovnick, supra note 30, at 270. But see Shewmon, supra note 21, at 15 ("Although it is commonly stated that [anencephalic] infants invariably die within a few days of birth, various large studies and a number of anecdotal reports of longer survivors cast serious doubt on this contention.").
Anencephaly also is "relatively common."33 Somewhere between 1,850 to 3,000 infants are born with anencephaly in the United States each year.34 This ranks anencephaly as the second most common congenital anomaly causing premature mortality, according to the Centers for Disease Control.35 Finally, anencephaly can be diagnosed with a high degree of certainty.36 Once the infant is born, anencephaly is obvious and easily diagnosed.37 Additionally, prenatal testing such as ultrasonographic and alpha-foetal protein (AFP) screening, which is becoming increasingly available, can detect almost all cases of anencephaly.38

Anencephalic organ donation has been proven to be successful. Published reports — from countries including the United States, West Germany and France — recount at least twenty-three kidney transplants using anencephalic infant donors since the early 1960s.39 Many of the transplants were successful.40 Renal transplants were especially successful in recipients aged eight to forty-four years old.41

The most celebrated cases involved Adrian Kantrowitz’s attempts to perform the world’s first human-to-human heart trans-
plant using anencephalic newborns' hearts.\textsuperscript{42} In 1966 Kantrowitz waited for an anencephalic infant's heart to stop beating before declaring death and performing the transplant. Once death occurred, the infant could not be resuscitated. Nevertheless, Kantrowitz found anencephalic heart donors to be a "realistic possibility."\textsuperscript{43} Less than two years later, he used an anencephalic newborn's heart for the first human-to-human heart transplant in the United States.\textsuperscript{44} The recipient survived only six and one-half hours, but Kantrowitz described the procedure as "technically successful."\textsuperscript{45}

B. The Need for Anencephalic Organ Donation

Anencephalic organ donation not only has demonstrated potential for medical success, it also would fulfill the critical needs of children with debilitating or otherwise fatal diseases, parents of anencephalic infants who wish to donate their infant's organs, and medical practice and research.

1. Organ Recipients

Significant advances have been made in pediatric transplantation.\textsuperscript{46} Children less than one year old have undergone successful heart, liver and kidney transplants.\textsuperscript{47} Experience in managing small patients and organs along with the development of new therapeutic agents promises continued improvement in survival rates.\textsuperscript{48} These advances offer hope to scores of children with otherwise fatal diseases. Each year, transplantation could help 300 to 500 children with end-stage renal disease; 400 to 1,000 children with liver failure; and 400 to 600 children with fatal forms of congenital heart disease, such as hypoplastic left heart syndrome.\textsuperscript{49}

\textsuperscript{42} Id. at 782.
\textsuperscript{43} Id.
\textsuperscript{44} Id.
\textsuperscript{45} Id. at 790.
\textsuperscript{46} See, e.g., Botkin, supra note 29, at 250 ("Major transplantation has become an acceptable alternative treatment for a variety of childhood diseases."); Landwirth, supra note 38, at 257 ("Significant progress has been made in the transplantation of small organs and the use of immunosuppressive agents in growing children.").
\textsuperscript{47} Botkin, supra note 29, at 250. But only pediatric liver and bone marrow transplantation are well developed. Sources, supra note 2, at 151. See infra notes 169-79 and accompanying text.
\textsuperscript{48} Botkin, supra note 29, at 250.
\textsuperscript{49} The estimates vary. See, e.g., Landwirth, supra note 38, at 257; Sources, supra note 2, at 151. Other types of transplantation are being developed that would benefit many
Although the demand for small organs is acute, the supply is critically low. The shortage is greater for infants than for children and adults. Most dying newborns are not suitable organ donors. Either their underlying disease, or the life support systems and drugs administered in neonatal intensive care makes their organs unusable. The pool of potential pediatric donors usually consists of children who die from child abuse, asphyxiation, sudden infant death syndrome and auto accidents. These donors number very few. For example, only about 1,200 children die in auto accidents each year. This shortage of organs is likely to worsen as transplantation techniques are perfected.

2. Parents of Anencephalic Infants

Many parents of anencephalics, like Baby Gabriel's, have urgently pressed physicians and hospital administrators to allow donation of their infant's organs. One mother who carried her anencephalic infant to term and wanted the infant's organs

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50. Sources, supra note 2, at 156. Congress responded to the severe shortage of viable organs for transplantation in 1984 with the National Organ Transplant Act. Pub. L. No. 98-507, 98 Stat. 2339 (1984) (codified as amended at 42 U.S.C. §§ 201, 273-74e (Supp. IV 1986)). The Act was passed to stimulate research and nationally integrate organ procurement procedures. It also ordered that a Task Force on Organ Transplantation be formed to help increase organ donation. Note, Organ Donors, supra note 17, at 1531. Among the task force's findings was that at any given time, there are an estimated 8,000 to 10,000 people waiting for an organ donation. UNIF. ANATOMICAL GIFT ACT, 8a U.L.A. 2, 3 (Supp. 1988) (quoting the task force's 1986 report "Organ Transplantation: Issues and Recommendations").

51. Sources, supra note 2, at 154.
52. Caplan, supra note 23, at 121.
53. Sources, supra note 2, at 151.
54. Id. This number is expected to decrease because of seat belt laws and improved methods of carrying children in cars. Transplant Policy Center, supra note 36, at 29; Note, Organ Donors, supra note 17, at 1531.
55. See, e.g., Sources, supra note 2, at 152 ("Development of additional transplant therapies . . . will increase demand for organs for newborns and lead to the supply and distributional problems that now exist with pediatric livers and adult organs.") (footnote omitted).
56. See, e.g., Brain-Deficient Baby, supra note 18, at C19, col. 1 (parents pleased they could donate heart valves, eyes and corneas of anencephalic infant); New Attention Focused on Infant Donors, N.Y. Times, Dec. 14, 1987, at A18, col. 1 (parents persuade physicians to maintain anencephalic infant on respirator so its organs can be donated). Loma Linda has received more than 200 inquiries from parents and physicians representing parents about the possibility of using organs of anencephalic infants to save others' lives. Infant Transplant Program is Halted to Reassess Issues, N.Y. Times, Aug. 20, 1988, at 7, col. 1.
donated explained, "When we found out about the baby, that was devastating enough. But when we discovered that the organs would all be healthy and normal and that babies who need a liver or heart couldn't get them, well, that's when we started getting into it."\(^{57}\)

3. Medicine

Pediatric organ donations are crucial to gaining the necessary knowledge of basic biology for pediatric transplantation. Despite its advances, pediatric transplantation remains experimental.\(^{58}\) Not enough is known, for example, about the immune systems of very young infants or the ability of transplanted organs and tissues to support normal growth and development in a growing child or adolescent.\(^{59}\) The scarcity of organs and tissues also is slowing research in new areas, such as developing infant neural transplants to reverse age-related dementias such as Parkinson's disease.\(^{60}\)

C. The Core of the Controversy: Defining Death

Despite the need for organs of anencephalic infants, their procurement faces a formidable obstacle. The Uniform Anatomical Gift Act (UAGA)\(^{61}\) — now adopted in every state\(^{62}\) — mandates that removal of organs for transplantation occur only "upon or after death."\(^{63}\) This so-called "dead donor" rule draws anencephalic organ donation into an area of heated legal, medical and ethical debate: the definition of death.

1. The Heart-Lung Criteria

Traditionally, lay and medical communities alike followed

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57. Plan to Donate, supra note 18, at 16, col. 2.
58. See, e.g., Annas, supra note 3, at 38 ("Currently, [infant organ transplants] are extremely experimental . . ."); Sources, supra note 2, at 151 (Other than transplantation of livers and bone marrow, pediatric transplantation is not well developed.").
60. Id. at 125-26.
62. Id. (prefatory note).
63. The UAGA defines an anatomical gift as "a donation of all or part of a human body to take effect upon or after death." Id. § 1(1), at 4 (emphasis added). This so-called "dead donor" rule is stressed throughout the statute. For example, it provides: "If there has been an anatomical gift, a technician may remove any donated parts . . . after determination of death by a physician or surgeon." Id. § 8(c), at 15.
ancient custom and clear logic to determine death: they looked for the cessation of heartbeat and breathing. The common law articulated this heart-lung standard. But medical technology rendered it obsolete in certain situations. Mechanical respirators and related therapies were developed that could reverse the failure of respiration and circulation. Patients now could experience complete and irreversible loss of all brain functions but continue to exhibit artificially maintained cardiopulmonary activity. Traditional means of diagnosing death were inadequate for these permanently comatose patients.

These developments raised many new medical concerns. Physicians could not assure that appropriate care would be given to these patients or that artificial support would be replaced with “more fitting and respectful” behavior when a patient died. Doctors also were troubled about prolonging the grieving of families and allotting scarce and costly intensive-care facilities to patients who would never be resuscitated.

The development of organ transplantation in the 1950s and 1960s also triggered physicians’ interests in the definition of death. Because organs deteriorate quickly once respiration and circulation stop, the best organ donors are otherwise healthy persons who died from traumatic head injuries but whose breathing and circulation are artificially maintained. Physicians needed new criteria to determine death in these patients without removing them from life-support long enough for their organs to become nonviable.

2. The Brain-Oriented Criteria

The most important response to the medical concerns about diagnosing death in respirator-supported patients was a 1968 report of a Harvard Medical School ad hoc committee, now known as the “Harvard Criteria.” In this report, the committee proposed

64. Defining Death, supra note 26, at 5.
66. See Defining Death, supra note 26, at 22.
67. Id. at 24.
68. Id. at 23.
that the absence of brain functioning is an acceptable alternative criteria for determining death when respiratory and circulatory functions are being artificially maintained in an irreversibly comatose patient. It provided four criteria by which to determine the absence of brain functions.

Although the specific Harvard Criteria were criticized and refined, the medical community generally accepted the new “whole brain death” standard. In fact, the Harvard committee predicted that statutory changes in the law would not be necessary "since the law treats this question essentially as one of fact to be determined by physicians." It argued that legislation would be necessary only if “great controversy were engendered surrounding the subject and physicians were unable to agree on the new medical criteria.”

The committee’s worst scenario was realized. The new standard created confusion and controversy among the public and physicians. Fears arose that the brain death criteria would be used to enable premature organ transplantation. Public controversy...
brewed during the famous Karen Ann Quinlan case over brain death and the question of discontinuing life-support for patients in a persistent vegetative state. Confusion over the difference between permanent unconsciousness and death resulted in the misapprehension that there now were several levels of death. Finally, courts and legislatures produced widely divergent responses to the new brain death criteria. Some courts adhered to the traditional cardiopulmonary standard; others updated the criteria to include a whole brain death standard. Likewise, states adopted a "patch-work" body of death statutes.

The need for a uniform law was apparent. In 1980 — twelve years after the Harvard Criteria were published — the Uniform Determination of Death Act (UDDA) was drafted. Most

Id. at 1537 n.74.

A scenario that perhaps goes beyond even the public's worst fears is played out in the popular book and movie Coma, which depicts physicians who induce comas in patients undergoing minor surgery and reap huge profits from the sale of organs on the black market. R. Cook, Coma (1977); Coma (Metro-Goldwyn-Mayer 1978).


See generally Note, Organ Donors, supra note 17, at 1541-43 (discussing Quinlan). The Quinlan case focused public attention on the brain death criteria, breaking "new judicial ground by linking legal concepts of life, death, and quality of life to the validity of medical predictions." Id. at 1542. But these considerations are irrelevant to the determination of death. The issue in Quinlan was whether to discontinue treatment of a living patient who never would recover consciousness, not whether the patient was in fact, or should be considered, dead. See Defining Death, supra note 26, at 61 n.8 (withholding treatment of permanently comatose patients is a "distinct bioethical and legal issue receiving separate attention from the President's Commission").

Capron, supra note 34, at 7. The Harvard Criteria's use of the term "irreversible coma" reflects this confusion. The committee claimed its purpose was to "define irreversible coma as a new criterion for death." Harvard Criteria, supra note 70, at 337. But this definition embraces contradictory terms. While "coma" is a condition of living patients, it is the absence of any brain function which indicates death. See Defining Death, supra note 26, at 25.

See Defining Death, supra note 26, at 135-36. This judicial stance may have led to troubling results in some criminal cases. Physicians who terminated life-support were charged with murder, and homicide defendants argued that termination of life support and organ removal were the proximate causes of the victim's death. These arguments were uniformly rejected, however. Id. For discussions of these cases, see W. Lafave & A. Scott, Jr., Criminal Law § 7.1(d) (2d ed. 1986); Defining Death, supra note 26, at 136-39; Note, Organ Donors, supra note 17, at 1538-40.

See Defining Death, supra note 26, at 137-42.

See id. at 109-10.


The UDDA superseded the short-lived Uniform Brain Death Act (UBDA).
states have now adopted by statute or judicial decision a definition of death identical or similar to the one contained in the UDDA. \(^4\) The UDDA 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. A determination of death must be made in accordance with accepted medical standards." \(^5\)

The problem anencephalic organ donation poses is this: Under the UDDA's second, "whole brain" criteria for determining death, anencephalic infants continue to live while they exhibit residual brainstem activity. Removal of infant organs before total brain death would violate the UAGA's "dead donor" rule. \(^6\) It therefore would constitute murder under present law \(^8\) and the type of active euthanasia \(^8\) prohibited by the American medical community. \(^8\) However, the circulatory and respiratory systems of these infants are so poor that if physicians do not intervene until

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Unif. Brain Death Act, 12 U.L.A. 16, 16 (Supp. 1989). The UBDA was drafted by the Conference on Uniform State Laws and criticized because it failed to incorporate the cardiopulmonary standard in addition to the whole brain standard. Note, Organ Donors, supra note 17, at 1544. The UDDA was drafted through a joint effort of the National Conference of Commissioners on Uniform State Laws, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the President's Commission), the American Medical Association and the American Bar Association. Defining Death, supra note 26, at 160. The President's Commission reported that the uniform law sought to describe death as a single phenomenon; constitute incremental rather than radical change; create uniformity among people and situations; and be adaptable to advances in technology. id. at 57-61.

84. Twenty-three states and the District of Columbia have adopted the UDDA. See Unif. Determination of Death Act, 12 U.L.A. 310 (Supp. 1989) (table of jurisdictions that have adopted the act). Fifteen states have adopted similar provisions. See Comment, Anencephalic Infants as Organ Donors: Legal and Ethical Perspectives; 9 J. Legal Med. 449, 451 n.16 (1988) (listing the state statutes). And in several other states, judges have recognized a similar standard. Defining Death, supra note 26, at 61. Comment, supra at 451, n.16. The committee that proposed the 1987 UAGA decided that it was unnecessary to include the UDDA definition of death in the UAGA because almost all states have similar definitions by statute or judicial decision, and those that do not have been urged to adopt the UDDA by the Task Force on Organ Transplantation. Unif. Anatomical Gift Act (1987) § 3 (a)(3), 8a U.L.A. 2, 5-6 (Supp. 1990) (comments to section one).


86. See supra notes 61-63 and accompanying text.

87. See infra notes 234-42 and accompanying text.


89. Id. The House of Delegates of the American Medical Association endorsed this statement in 1973: "The intentional termination of the life of one human being by another — mercy killing — is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association." Id.
the newborns are legally "dead," their organs will deteriorate to the point of being physiologically unsuitable for transplantation. Thus, the current law lessens the possibilities of organ donation from anencephalic infants.

II. METHODS OF OBTAINING ANENCEPHALIC INFANT ORGANS

Various methods have been tested and proposed to circumvent the legal and medical obstacles to obtaining organs from anencephalic infants. The two basic approaches are: removing the infants' organs before total brain death (the immediate procurement approach), and preserving the infants' organs until whole brain death occurs (the intervention approach). Either approach entails a significant departure from the customary "comfort care" given to anencephalic babies, which usually includes warmth, nutrition and hydration.

A. The Immediate Procurement Approach

Some commentators advocate that surgeons should remove the organs of anencephalic newborns for transplant immediately after delivery and before total brain death. This immediate procurement approach avoids any deterioration of the organs and maximizes the potential for medically successful transplants.

Surgeons in West Germany removed the kidneys of an anencephalic infant before brain death without any legal ramifications. Surgeons involved in the procedure wrote, "[W]e think that one can treasure the principle [of a total brain death definition] and at the same time argue for a morally acceptable exception." Two American groups have supported this immediate procurement method. Physicians at Boston Children's Hospital

90. Caplan, supra note 23, at 123.
91. In addition, many task forces have been formed to examine the issue. They include task forces at the Washington University Medical Center in St. Louis, University of Virginia Medical Center, the Child Neurology Society, the American Academy of Pediatrics, and the American Academy of Neurology. Walters & Ashwal, supra note 16, at 20.
92. See Sources, supra note 2, at 155.
93. See Holzgreve, Beller, Buchholz, Hansmann & Köhler, Kidney Transplantation from Anencephalic Donors, 316 New Eng. J. Med. 1069, 1069 (1987) [hereinafter Kidney Transplantation]. West German courts have determined that anencephalic fetuses are never alive despite the presence of a heart beat and allow these pregnancies to be terminated at any time. Id.
devised a protocol in 1986 for the immediate removal of organs after birth. The protocol was never implemented, however, because the procedure is currently illegal. The Michigan Ethics and Social Impact Committee at the Transplant Policy Center also adopted the immediate procurement position in a 1988 report. The committee asserted that it does not "seek to resolve the underlying dilemma presented by alternative conceptions of brain death . . . . [W]e cannot say with confidence whether anencephalic infants should be thought of as alive or dead . . . . We defend not an intermediate position in the conflict . . . but a position that bypasses that conflict." The committee explained that anencephaly is a condition so special, so very different from 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.

Unlike the Michigan group, most commentators have confronted the whole brain death problem. One possible solution is amending the law to enable organ procurement before anencephalic infants meet whole brain death criteria.

1. Amending the UDDA

Some philosophers argue that the whole brain death standard is outmoded and should be replaced by a cortical or "higher brain" standard. Their position is based on the premise that

96. Id.
97. Transplant Policy Center, supra note 36, at 28. The committee recommending this policy included "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." Id.
98. Id.
99. Id.; see also Landwirth, supra note 38, at 257 (noting that kidneys have been transplanted from anencephalic infants artificially supported at birth but removed before brain death).
100. See, e.g., Green & Wikler, Brain Death and Personal Identity, 9 PHIL. & PUB. AFF. 105, 131 (1980) ("[I]t is loss of upper brain function which marks the person's death. Death of the brain stem is no more constitutive of death simpliciter than death of the kidneys or of other vital organs."); Veatch, The Whole-Brain-Oriented Concept of Death: An Outmoded Philosophical Formulation, 3 J. THANATOLOGY 13, 29 (1975) (arguing that patients or their agents should be given the choice of a cardiopulmonary, brain-oriented, or neocortical standard for death). See generally Defining Death, supra note 26, at 38-39
personhood hinges on cognitive function,\textsuperscript{101} and therefore an absence of "higher brain" function constitutes an absence of life. Under this standard, anencephalic infants would be considered dead despite their brainstem activity.

Doctor Michael Harrison has suggested adoption of a new "brain-absent" criterion for death that is limited only to anencephalic infants and has the same medical-legal implications as whole brain death.\textsuperscript{102} Doctor Harrison argues that the whole brain definition of death was adopted to protect only comatose patients who may recover brain functioning. He asserts that this precaution does not apply to anencephalic infants, who can never have the physical structure necessary for higher brain activity or cognitive function. Therefore, creating a special category for anencephalic infants would be consistent with the policies underlying the general requirement of whole brain death.\textsuperscript{103}

Another possible solution would be to modify the UDDA's definition of death to include anencephaly. California Senator Milton Marks introduced a bill in February of 1986 that would amend the UDDA to state that "an individual born with the condition of anencephaly is dead."\textsuperscript{104} The senator later modified his bill, however, to propose that a state health advisory board make recommendations concerning the care of infants with life-threatening conditions, including the "feasibility and necessity" of infant organ transplants, the donation of organs from anencephalic infants, and any "necessary changes" in the UDDA or UAGA.\textsuperscript{105}

Finally, a Working Party of the Medical Royal Colleges in Great Britain redefined the determination of death for anencephalic infants as cessation of spontaneous respiration (apnea).\textsuperscript{106} They found that although brainstem function tests are

(explaining "higher brain" formulations).

\textsuperscript{101} See, e.g., Green & Wikler, \textit{supra} note 100, at 127 ("[A] person ceases to exist with the destruction of whatever processes there are which normally underlie that person's psychological continuity and connectedness."); Veatch, \textit{supra} note 100, at 29 (stating that the essential element of personhood is "capacity for experience and social interaction"). \textit{But see infra} notes 142-46 and accompanying text.

\textsuperscript{102} Harrison, \textit{The Anencephalic Newborn as Organ Donor}, \textit{HASTINGS CENTER REP.}, April 1986, at 21, 21.

\textsuperscript{103} Id. \textit{But see} Arras & Shinnar, \textit{Anencephalic Newborns as Organ Donors: A Critique}, 259 J. A.M.A. 2284, 2285 (1988) (arguing that Harrison reinterpreted the original intent of the whole brain definition of death).

\textsuperscript{104} Capron, \textit{supra} note 34, at 6.

\textsuperscript{105} Id.

\textsuperscript{106} Milunsky, \textit{Harvesting Organs for Transplantation From Dying Anencephalic Infants}, 82 \textit{PEDIATRICS} 274, 275 (1988).
useful to determine brain death in adults, the tests are "inapplicable when the forebrain itself is missing."\textsuperscript{107} They reasoned that if brain death plus cessation of apnea is recognized as death in adults, by analogy, "the absence of the forebrain in these infants plus apnea would similarly be recognized as death."\textsuperscript{108}

2. Amending the UAGA

Another way to enable anencephalic organ donation before whole brain death would be to modify the UAGA. This approach would avoid the broader legal implications of redefining death. A cortical death standard, for example, would encompass all permanently comatose patients, even if they could breathe on their own for many years. Arthur Caplan has suggested that the UAGA’s definition of donor should include "those who are brain dead or those suffering from anencephaly."\textsuperscript{109} In addition, New Jersey Assemblyman Walter Kern, Jr. proposed a bill in October 1986 to allow parents to donate the organs of anencephalic infants who did not meet the UAGA requirement that patients must be "dead" before organs are removed for transplantation.\textsuperscript{110}

B. The Intervention Approach

The second major approach to anencephalic organ donation involves developing procedures that preserve the infants’ organs until total brain death occurs, and only then permitting organs to be retrieved. This intervention approach is often used for adult donors.\textsuperscript{111} Two methods can be used to preserve the infant’s organs until brain death: life-support and cooling.

1. Maintaining Infants on Life Support Systems

An international, interdisciplinary group of experts convened in London, Ontario in January 1987 to discuss the use of anencephalic infants as organ donors.\textsuperscript{112} The group agreed that anencephalic organ donation was ethical only upon determination

\begin{itemize}
\item \textsuperscript{107} Id.
\item \textsuperscript{108} Id.
\item \textsuperscript{109} Caplan, supra note 23, at 140.
\item \textsuperscript{110} Capron, supra note 34, at 60.
\item \textsuperscript{111} E.g., Sources, supra note 2, at 156, 158; Walters & Ashwal, supra note 16, at 23.
\item \textsuperscript{112} Annas, supra note 3, at 36.
\end{itemize}
of death using established whole brain death criteria.\textsuperscript{113} Life-support would be used to preserve the infants' organs until such death occurred.\textsuperscript{114}

The life-support theory was first implemented in Baby Gabriel's case at the Children's Hospital in Western Ontario and at Loma Linda University Medical Center in California.\textsuperscript{116} The success of the Baby Gabriel case prompted both institutions to formally adopt protocols for transplanting the organs of anencephalics.\textsuperscript{117} Loma Linda reconsidered a protocol that was rejected in 1986 because there was no assurance that an anencephalic infant attached to a respirator would die within a reasonable time.\textsuperscript{118} A modified proposal was formulated in December 1987.\textsuperscript{119}

This protocol permitted parents to decide whether to donate their infant's organs once anencephaly was diagnosed.\textsuperscript{120} If parents made a "firm statement" of their desire to donate their infant's organs and signed a consent form, the infant was given traditional comfort care plus respirator support for a maximum of seven days after birth.\textsuperscript{121} Only those who met established brain death criteria within seven days were eligible for organ donation.\textsuperscript{122} The seven-day limit was chosen because ninety-five percent of anencephalic infants die within seven days. Physicians were to examine the infant twice a day and perform the "weaning test"\textsuperscript{123} to determine whether brain death had occurred. If brain

\begin{itemize}
\item \textsuperscript{113} Id.
\item \textsuperscript{114} Id.
\item \textsuperscript{115} Id. at 37.
\item \textsuperscript{116} See Annas, \textit{supra} note 3, at 37 (describing the Children's Hospital's protocol); Walters & Ashwal, \textit{supra} note 16, at 22 (describing Loma Linda's protocol). The protocol of the Children's Hospital required that the parents agree, before birth, that: (1) the infant will be resuscitated; (2) periodic testing will be done to determine the established definition of brain death; (3) organ donation will be acceptable once brain death criteria are met; and (4) after a definite time limit (to be determined by the parents but no more than fourteen days), the infant will be removed from the ventilator and permitted to die. In addition, because it is unknown whether anencephalic infants may experience pain, low doses of morphine are to be administered to prevent any suffering. Annas, \textit{supra} note 3, at 37.
\item \textsuperscript{117} Walters & Ashwal, \textit{supra} note 16, at 22.
\item \textsuperscript{118} Id. at 23.
\item \textsuperscript{119} Id.
\item \textsuperscript{120} Id.
\item \textsuperscript{121} Id.
\item \textsuperscript{122} Physicians often use a so-called "weaning test" to determine brain death in patients on ventilators. Ventilation is discontinued, and physicians wait for carbon dioxide to accumulate in the blood until the respiratory center, controlled by the brainstem, would normally initiate breathing. Brain death is established if the brainstem does not respond
\end{itemize}
death was confirmed by two physicians not involved in direct care of the potential organ recipient, the infant was considered for organ donation. The protocol used for all organ donations was followed, including a family consent form. Those infants who did not die within seven days were removed from ventilation and given comfort care until death did occur.

When only one of six infants met the criteria of brain death within seven days, Loma Linda physicians again changed the protocol. They explained that "[u]pon 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." Under the modified protocol, six infants were given only warmth, nutrition and hydration at birth. The infants were not placed on life-support at birth, but only after cardiac-respiratory failure suggested imminent death. The infants were then placed on a ventilator which would preserve their organs for transplantation for only twenty-four hours. If brain death criteria were met, ventilation continued and confirmation of brain death was made by an outside neurologist referee. If brain death criteria were not met, the infants were returned to basic care where they were withdrawn from mechanical ventilation and allowed to die without further intervention.

2. Gradual Cooling of Infants

Doctors Fletcher, Robertson and Harrison suggest an alternative method of preserving the infants' organs until total brain death. They propose cooling the anencephalic newborn "by surface applications of cooling media or by cool intravenous solutions." Although this procedure may hasten brain death by contributing to cerebral swelling, its proponents claim that it is when the carbon-dioxide level in the blood is sufficient to stimulate respiration. Oxygen is maintained in the blood during this test to preserve viability of organs; ensure that low-oxygen levels do not create the false impression that the brainstem is dead; or cause the death of the brainstem. Fost, Organs from Anencephalic Infants: An Idea Whose Time Has Not Yet Come, HASTINGS CENTER REP., Nov. 1988, at 5, 6-7.
morally justified because it does not harm the infants because they are "beyond the point of injury."131 Doctor Kantrowitz employed this cooling method when he used an anencephalic infant's heart for the first human-to-human heart transplant in the United States.132

III. THE CASE AGAINST ANENCEPHALIC ORGAN DONATION

Programs and proposals to obtain organs from anencephalic infants have provoked strong opposition on all fronts: legal, ethical, medical and political. In response to these forces, all efforts in the United States to use anencephalic infants as organ donors have stopped.133 Loma Linda suspended its ventilation program in August 1988.134 What follows is an overview of the most common objections.

A. The Legal Problem: Redefining Death

Proposals to amend the existing death statutes have been objected to because such changes violate the spirit of the UDDA and represent a radical change in legal policy that society will not accept. Doctor Alexander Morgan Capron, an outspoken opponent of anencephalic organ donation, claims that proponents of these amendments are confused about existing law because the term "brain dead" implies that there are two kinds of death: brain death, and real or cardiopulmonary death.135 Since the proponents already recognize a break with the traditional "definition" of death, he argues, they can justify these amendments as simply another acceptable "definition" of death rather than a radical change.136 Doctor Capron and others contend that death is a single concept. Although death now can be determined by brain or cardiopulmonary standards, death is more than just what we choose to call it.137 Therefore, there is no justification for these "as

131. Id. at 159.
132. Annas, supra note 3, at 38.
133. E.g., Caplan, supra note 23, at 129 ("[T]he [kidney] transplants stopped when legal concerns surfaced regarding the eligibility of anencephalic infants for organ donation.").
135. Capron, supra note 34, at 7.
136. Id.
137. Id. at 7-8; Willke & Andrusko, Personhood Redux, HASTINGS CENTER REP., Nov. 1988, at 30, 33. J.C. Willke is president of the National Right to Life Committee; Dave Andrusko is editor of the National Right to Life News. Although it is important to
good as dead" definitions.\textsuperscript{138} Dying anencephalic infants are just that, dying: they are not dead.

The President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the President's Commission) expressly rejected the "higher brain" formulations of death as too radical a departure from traditional standards in a 1981 report on defining death.\textsuperscript{139} The Commission concluded that finding death when spontaneous breathing and heartbeat were present would imply that the traditional cardiopulmonary standard had always been wrong, even before medical technology rendered it obsolete in some circumstances.\textsuperscript{140} The President's Commission described its position on defining death as "deliberately conservative," recognizing only new diagnostic measures of death, not a new concept of death.\textsuperscript{141} Because it did not find a great enough consensus to radically revise the concept of death, "a matter so fundamental to a society's sense of itself — touching deeply held personal and religious beliefs — and so final for the individuals involved,"\textsuperscript{142} the Commission favored the objective whole brain death criteria.\textsuperscript{143}

B. The Ethical Problem: Respect for Human Life

Many ethicists and physicians strongly object to what they perceive as the utilitarian underpinnings of all approaches to anencephalic organ donation: namely, that it is morally justified
because it produces the greatest good for the greatest number of people.

1. Personhood

Many commentators specifically oppose the claim that obtaining organs from anencephalic infants is justified because these infants are not persons. The infants are said to lack personhood because unlike other permanently unconscious patients, they have no past cognitive function and lack the physical capacity ever to have any.144

The President's Commission rejected this argument because there is no agreement among philosophers, physicians or the public about what constitutes personhood.146 Other commentators argue that society must maintain a clear definition of legal personhood that avoids the ambiguities of cognition if society is to preserve its symbolic commitment to human life.146 These commentators argue that we must not allow "the possibility that unwanted persons can be defined out of existence if it serves the greater good."147 Harrison, who proposed creating a special brain absent category of death, also rejects the personhood argument. He claims, for example, that this argument belittles the pregnancy and may adversely affect how the family and infant are treated.148

2. The Slippery Slope

Many critics argue that the immediate procurement approach, including its personhood rationale, will set a dangerous precedent. They fear that redefining death or changing the requirements for organ donation will result in the "gradual exploitation of the vulnerable and progressive brutalization of medicine and society."149

144. For example, Loma Linda physician Dr. Leonard Bailey called an anencephalic infant "a nonperson human derivative, a resource we should be able to capitalize on." Goldsmith, supra note 35, at 1671; see Martin, Gonzalez, West, Shwartz & Sutorius, Homotransplantation of Both Kidneys From an Anencephalic Monster to a 17 Pound Boy with Eagle Barrett Syndrome, 66 SURGERY 603 (1969). See generally Sources, supra note 2, at 157 (outlining the personhood argument); supra text accompanying notes 101-102 (Some philosophers use the personhood argument to support a cortical definition of death.).
146. E.g., Sources, supra note 2, at 157-58.
147. Fost, supra note 122, at 7.
148. Harrison, supra note 103, at 22.
149. Botkin, supra note 29, at 254; see also Capron, supra note 34, at 8 ("[I]f soci
The most obvious group to be swept in under such legislation is infants with other neural tube anomalies that are equally fatal but may allow longer survival, such as hydrencephaly (a condition in which an infant has normal brain development early in gestation until an event such as infection destroys the cerebral hemispheres and replaces them with fluid) and microcephaly (a condition in which the infant has a very small head). The other group in danger are those persons who, like anencephalic infants, continue to breathe on their own yet have no "valid" interests in living due to limited cognitive functioning, such as people who are in a persistent vegetative state, have Alzheimer's disease or are severely retarded.

This concern affects those who practice the intervention approach as well. Loma Linda's Chief of Neonatology, Dr. Joyce Peabody stated, "[T]he slippery slope is real." She noted that physicians have contacted Loma Linda suggesting infants with less severe defects than anencephaly be enrolled in the program.

3. A Means to an End

Writers also argue that anencephalic organ donation is morally wrong apart from its consequences. They claim that these infants are being used as receptacles for organs. One commentator points out that the premise of western medical ethics is to preserve life at all costs, a principle rooted in Christian and Judaic theology that prohibits taking human life even to benefit others. Others appeal to Kant's Categorical Imperative, which calls for humans to be treated as ends in themselves and never used solely as a means to an end. This Kantian argument has been aimed at the intervention approach in particular. Gilbert Meilaender, a professor of religion at Oberlin College, articulates this fear: "[T]he anticipated organ donation tempts us to treat
[anencephalic newborns] in ways we otherwise would not — which is, I fear, a temptation to use this child simply as a means to another (admittedly desirable) end. . . . What we accomplish thereby would be good; what we do would not.”

C. The Medical Problem: Uncertainties

Fueling these ethical objections are several unresolved medical questions concerning anencephalic organ donation. Little is known about anencephaly because of its certain, swift fatality or the success of ventilation programs such as Loma Linda’s.

1. Brain Death

Some critics suggest that anencephalic infants theoretically should not die while on respirators. Many commentators doubt whether brain death can be determined in these infants by presently accepted criteria. Some have questioned whether Loma Linda physicians properly confirmed brain death in the infants in its program. The Task Force on Brain Death in Children, which contributed to the establishment of the existing criteria for determining infant brain death, limited its discussion to infants more than seven-days old. Without proper determination of brain death, some argue that ventilation programs are a subterfuge, a way to carry out active killing while avoiding the difficult ethical and legal implications of that approach.

158. Shewmon, supra note 21, at 15; Willke & Andrusko, supra note 137, at 31.
159. E.g., Fost, supra note 122, at 6-7; Willke & Andrusko, supra note 137, at 31.
160. Fost, supra note 122, at 7; Willke & Andrusko, supra note 137, at 31. In addition, the cooling method may create a reversible brain-death state. All brain-death criteria require that patients are not hypothermic. Walters & Ashwal, supra note 16, at 20.
161. See Report of Special Task Force: Guidelines for the Determination of Brain Death in Children, 80 PEDIATRICS 298 (1987); see also Volpe, Brain Death Determination in Newborn, 80 PEDIATRICS 293, 296 (1987) (“The two essential requirements for the diagnosis of brain death, ie [sic], the establishment of cessation of cerebral and brainstem functions and the demonstration of irreversibility, are extraordinarily difficult to fulfill in the newborn and young infant . . . . Clearly, more information is needed . . . . ”). But see Walters & Ashwal, supra note 16, at 25:

The literature on brain death and research at Loma Linda on determination of brain death in newborns suggest that the recent Special Task Force guidelines can be extended to include the preterm and term infant and that the diagnosis of brain death can usually be determined solely on a clinical basis.
162. See Caplan, supra note 23, at 137.
2. Misdiagnosis

The possibility of misdiagnosis is often used to support critics' slippery slope arguments. There is no agreement on specific criteria defining anencephaly. In most cases it is obvious, but in many it is not. Anencephaly lies on a continuum with other congenital neural defects; while some anencephalic infants have no cerebral tissue, others have a negligible amount. In addition, the risk of misdiagnosis accompanies any condition, no matter how obvious. In fact, there are several reported cases of the misdiagnosis of anencephaly, including one that may have occurred in Loma Linda's anencephalic organ donation program.

3. Efficacy

Another problem that some commentators note is that insufficient evidence exists to show that anencephalic infants will be effective organ donors. Doctor Alan Shewmon, Assistant Professor of Pediatrics and Neurology at the University of California at Los Angeles (UCLA) Medical Center, provides a detailed analysis of this issue. He "optimistically" estimates that no kidneys, nine hearts and two livers could be obtained today from anencephalic infant donors. In ten years, he projects twenty-five kidneys,

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163. Shewmon, supra note 21, at 11-12.
164. Id. at 11.
165. Fost, supra note 122, at 8; see also Shewmon, supra note 21, at 11-12 (describing conditions that are closely related to anencephaly).
166. Fost, supra note 122, at 8.
167. See Baird & Sadovnick, supra note 30, at 270: While conducting this study, it became obvious that it is important to verify the diagnosis of anencephaly among those infants reported to survive longer than 7 days. One infant initially coded as anencephaly, who survived over 4 months, had hydranencephaly rather than anencephaly, and another who lived for 12 days actually had amniotic band syndrome mimicking anencephaly.
168. See Willke & Andrusko, supra note 137, at 32 ("[O]ne baby entered into [Loma Linda's] protocol was later referred back to an out-of-state medical center when [Loma Linda] doctors determined the baby was not a true anencephalic." (citing telephone interview with Richard Schaefer (Jul. 6, 1988))).
169. See Shewmon, supra note 21, at 15-17; see also Annas, supra note 3, at 38 (questioning the success of infant organ transplants and the viability of anencephalic newborns as a source of organs in the future); Holzgreve & Beller, supra note 94, at 961 ("'[G]radual cooling of the body . . . does not yield viable organs . . . .'"; Sources, supra note 2, at 155-56 ("'Whether tissues from anencephalics would always be metabolically or histologically sound for transplantation remains to be proven, since anencephalics are known to have hypoplastic cells in tissues.'").
170. Shewmon, supra note 21, at 17.
twelve hearts and seven livers may be obtained.\textsuperscript{171}

First, Professor Shewmon estimates that because anencephalic infants tend to be born prematurely and have intrauterine growth retardation, around sixty percent of the infants will be “too small to provide useful organs for transplantation.”\textsuperscript{172}

Second, he assumes that only two-thirds of parents involved will wish to donate their child’s organs.\textsuperscript{173}

Third, he estimates that up to fifty percent of the infants have gross associated malformation of at least one other organ system. Fourth, claiming that the success of infant kidney donations has been poor,\textsuperscript{174} he cites difficulties with the organ referral system: including ensuring blood type compatibility, geographic proximity, and unmedicated donors.\textsuperscript{175} Fifth, he factors in the paucity of experience with pediatric transplantation.\textsuperscript{176} And finally, he predicts that prenatal screening will result in the termination of half of all anencephalic fetuses.\textsuperscript{177}

Loma Linda’s experience substantiates some of Professor Shewmon’s concerns. One reason cited for the program’s moratorium was its lack of success.\textsuperscript{178} Only two infants of the twelve enrolled in its program were determined brain dead within the established seven days and thus eligible donors. The two potential donors were not used, however, because for various reasons recipients were not available.\textsuperscript{179}

\begin{itemize}
\item \textsuperscript{171} Id.
\item \textsuperscript{172} Id. at 15.
\item \textsuperscript{173} Id. at 16.
\item \textsuperscript{174} Id. at 16-17.
\item \textsuperscript{175} Id. at 17. One commentator states that approximately ninety-five percent of parents whose fetuses are diagnosed as anencephalic elect to abort the fetuses. Shewmon, supra note 21, at 12. The significant role of abortion in limiting the availability of anencephalic infants as organ sources may diminish, however, if the trend toward permitting states to restrict abortion continues. See Webster v. Reproductive Health Services, 109 S. Ct. 3040 (1989) (narrowing Roe v. Wade, 410 U.S. 113 (1973), which held that the constitutional right to privacy protects and includes the right of women to choose whether or not to bear a child).
\item \textsuperscript{176} See Goldsmith, supra note 35, at 1671. Dr. Joyce Peabody, Chief of Nephrology at Loma Linda, told the Los Angeles Times that: “Certainly, if the only outcome you are looking at is the number of solid organs transplanted, our program has failed, and failed dismally.” Id.
\item \textsuperscript{177} Id. One infant’s heart was not used because a recipient could not be found. In the other case, a heart recipient was found but the blood types were not compatible. Recipients were found waiting for the infants’ livers. But when a liver became available one potential recipient was suffering from an infection, another was in a hospital that was performing another transplant that day and could not do a second, and a third was in a hospital that wanted to avoid the news media. Id.
\end{itemize}
4. Prolonged Survival

Another concern of critics is that respiratory support may prolong the infants’ survival. One pediatric intensive care specialist called the ventilation programs “futile and inhumane.” The concern over the use of mechanical ventilators appears two-fold. Some are worried that respirator support will promote the infants’ long-term survival. One of Loma Linda’s infants lived for two months after the respirator was removed, another factor behind the program’s suspension. Others believe the programs will prolong the infants’ dying process and possibly expose them to pain. Loma Linda adjusted its protocol in 1988, and suspended its program in part because it wanted to avoid accusations of “organ farming.”

D. Policy Questions: Weighing the Costs

1. Resource Allocation

The cost of anencephalic organ donation must be considered in light of the competing demands for other types of health care and research for children. Doctor Capron claims that amending the Uniform Anatomical Gift Act to allow for organ removal from

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180. Annas, supra note 3, at 37.
181. See, e.g., Annas, supra note 3, at 36.
182. See Blakeslee, Infant Transplant Program is Halted to Reassess Issues, N.Y. Times, Aug. 20, 1988, at 7, col. 1. Doctors Willke and Andrusko claim, without support, that parents are withdrawing their consent from ventilation programs when their anencephalic infants do not become brain dead within several days. Willke & Andrusko, supra note 137, at 31.
183. E.g., Meilaender, supra note 157, at 23. Former U.S. Surgeon General Doctor C. Everett Koop, stated at the 1982 Hearing on Handicapped Newborns, before the Subcommittee on Select Education of the U.S. House of Representatives Committee on Education and Labor: "Some of nature's errors are extraordinary and frightening ... but nature also has the kindness to take them away. For [anencephalic] infants, neither medicine nor law can be of any help. And neither medicine nor law should prolong these infants' process of dying." PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 220 n.18 (1983) [hereinafter DECIDING TO FOREGO TREATMENT].
184. See Shewmon, supra note 21, at 15 (There is no "logical or physiological basis for the claim of some that an anencephalic infant can neither feel nor experience pain 'by definition.'"); see also Annas, supra note 3, at 38 ("If ... medical maintenance causes prolonged ... suffering in anencephalic infants, their use as organ donors would be unacceptable."). Most commentators, however, believe that anencephalic infants are incapable of experiencing pain. See, e.g., Fost, supra note 122, at 5; Sources, supra note 2, at 159.
185. See supra notes 125-28 and accompanying text.
anencephalics would lead to adoption of several protective measures that would "unnecessarily encumber the process of organ retrieval, increasing its costs and reducing its yield." Loma Linda President Doctor David B. Hinshaw estimated the total cost of its program at about $250,000. This figure includes the cost of the commercial air ambulance used to transport potential donor infants, the transport team, care during the infants' lives, and associated costs.

2. The Organ Donor System

There is a fear that using anencephalic infants as organ donors would undermine the public's trust in transplantation and the organ donor system. They are concerned that anencephalic donations may cause the public to suspect that other dying persons or persons deemed to have no interests in living may be used as nonvoluntary donors. Professor Capron claims that treating anencephalic infants as suitable organ donors would confuse the definition of "death" and cause relatives and health care personnel to become uncertain of all organ donations. Doctors Willke and Andrusko write, "How ironic it would be if in tampering with the definition of death to allow removal of organs from anencephalic infants, ethicists and transplant surgeons kill the goose that transplants the golden egg."

There also are fears that anencephalic organ donation will prompt abuses in the system, further undermining the public's trust. For example, physicians may pressure parents into carrying their child to term or manipulate the time and manner of the birth. Also, parents may sell the organs of their anencephalic infants.

3. Protecting Parents and Health Care Personnel

Some argue that the psychological cost to parents and health

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188. Id.
190. Capron, supra note 34, at 9.
191. See id. at 8.
192. See id. at 7.
193. Willke & Andrusko, supra note 137, at 33.
194. Botkin, supra note 29, at 254; Capron, supra note 34, at 8.
195. Comment, supra note 84, at 454. One commentator notes that making such practices illegal would be an effective deterrent to such sales. Id.
care personnel may be too great. Parents may suffer through not only the tragedy of their infant's condition, but also the disappointment of a failed transplant or lack of recipient. Some commentators also consider the harmful effect upon health care personnel in this situation. Publicity and political pressure created tension among Loma Linda's staff and undermined morale — another reason cited by Loma Linda officials for its program's suspension.

IV. THE COMPETING INTERESTS: BALANCING BENEFICENCE AND RESPECT FOR LIFE

Three parties are involved in this debate: the infants, the parents and society as a whole. Only when these parties' interests are considered separately can the objections to obtaining organs from anencephalic infants properly be evaluated.

A. The Infants' Interests

Theoretically, infants possess the same constitutional rights as adults, including the right of privacy and self-determination. However, because infants cannot express their interests, adults must decide their fates. In cases presenting medical-treatment issues, courts have used the "best interests" standard to protect infants. Under this standard, the President's Commission recommended that decision-makers must determine an infant's best interests by assuming the infant would want what a reasonable person in similar circumstances would want. The President's Commission cautioned decision-makers to evaluate the benefits and burdens from the infant's perspective and not impose their own values on the infant.

196. Annas, supra note 3, at 38; Willke & Andrusko, supra note 137, at 33.
198. Note, Organ Donors, supra note 17, at 1550.
200. Id.
201. Deciding to Forego Treatment, supra note 183, at 136.
202. See id. at 134-36
203. Id. at 219.
Withholding treatment and providing only "comfort care" has been considered in the best interest of anencephalic infants since there is no medical solution to their problem.\textsuperscript{204} This practice complies with the President's Commission's determination that it may be in an infant's best interest to withhold "clearly futile therapies" if that infant cannot be treated and will live only for hours or days, such as anencephalic infants.\textsuperscript{205} The Commission noted, however, that "[j]ust as with older patients, even when cure or saving of life are out of reach, obligations to comfort and respect a dying person remain."\textsuperscript{206} It recommended that these infants be provided relief from suffering, including feeding and medication for pain and sedation if necessary.\textsuperscript{207}

Professor Capron and others argue that as one of society's "most vulnerable patients,"\textsuperscript{208} the anencephalic infant's best interest precludes any shortening or prolonging of life. He states: "Unconsenting, incompetent patients who have never had a chance to express their views about whether, if near death but not yet dead, they would want their bodies cut up for purposes of organ donation, are the least suitable source [for organ donation]."\textsuperscript{209}

Although the "best interests" standard proves useful in most cases,\textsuperscript{210} notably where infants may find their lives meaningful despite their severe handicaps,\textsuperscript{211} it is problematic when applied to anencephalics. Because anencephalic infants lack any capacity or potential for human life, it is impossible to determine their best interests with respect to organ donation.\textsuperscript{212} It would be just as reasonable for these infants to wish to sacrifice themselves for the good of their parents and the persons whose lives they may save as it would be for them to reject interventions to enable organ donation. Any decision about the children's best interests would necessarily be an imposition of the decision-maker's values: The infants, who lack awareness of both their condition and what life holds for them, neither have nor will have any "views" of their own. The anencephalic infant, therefore, has no interests upon which to base

\textsuperscript{204} Walters & Ashwal, supra note 16, at 21.
\textsuperscript{205} See Deciding to Forego Treatment, supra note 183, at 219.
\textsuperscript{206} Id. at 220.
\textsuperscript{207} Id.
\textsuperscript{208} Capron, supra note 34, at 8.
\textsuperscript{209} Id.
\textsuperscript{210} Walters & Ashwal, supra note 16, at 21.
\textsuperscript{211} See Deciding-to Forego Treatment, supra note 183, at 219 n.79.
\textsuperscript{212} See Caplan, supra note 23, at 131; Walters & Ashwal, supra note 16, at 21.
a decision about organ donation.\textsuperscript{213} The decision whether to use their organs must reflect the interests of others — namely, parents and society.

\textbf{B. The Parents' Interests}

The law presumes that parents are the most appropriate decision-makers for their children.\textsuperscript{214} Common law — reflecting the philosophy of Hobbes, Locke and Mill — considered children their parents' chattels. Parents controlled, educated and provided for their children in return for obedience, while children had few rights, if any.\textsuperscript{215} Today, parents possess the more limited right of parental autonomy. Developed under constitutional principles of religious freedom, due process and right of privacy, this right allows parents to decide how their family shall live without excessive interference from the state.\textsuperscript{216}

Accordingly, most medical decisions concerning minors rests with parents.\textsuperscript{217} Children often cannot effectively consent to medical treatment, and in most cases, parents are present, concerned and eager to cooperate with physicians.\textsuperscript{218} Courts rarely review parents' decisions if the following conditions exist: (1) the parents are choosing from professionally accepted treatments; (2) the child's disease or condition is not severe or life-threatening; (3) it is not possible to delay decisions about treatment until the child reaches maturity; and (4) parents have a reasonable concern that the risks of treatment outweigh its benefits, even if withholding that treatment may be life-threatening.\textsuperscript{219} In addition, parents generally may decide how to dispose of their child's body,\textsuperscript{220} whether their child's organs will be donated,\textsuperscript{221} and whether their

\begin{footnotes}
\footnote{213. See Walters & Ashwal, \textit{supra} note 16, at 21. Several commentators believe anencephalic infants have no interests at all. See Caplan, \textit{supra} note 23, at 138 ("[T]here is no meaningful sense in which anencephalic infants can be said to have any of the properties associated with interests . . . "); Transplant Policy Center, \textit{supra} note 36, at 29 ("[T]here are no intrinsic interests of anencephalics to be defended.").

214. See \textit{Deciding to Forego Treatment}, \textit{supra} note 176, at 212.


216. \textit{Deciding to Forego Treatment}, \textit{supra} note 183, at 212 n.62.

217. \textit{Id.} at 213.


219. \textit{Id.} at 213.


221. See \textit{Unif. Anatomical Gift Act} \S 3(a)(3), 8a U.L.A. 13 (Supp. 1990).}

child can participate in research.\textsuperscript{222}

However, infants also are under the \textit{parens patriae} power of the state. The \textit{parens patriae} doctrine, "literally 'parent of the country'"\textsuperscript{223} gives the state standing to protect the health, comfort and welfare of its citizens.\textsuperscript{224} It originates from the English common law, where the King was "guardian to persons with legal disabilities such as infants, idiots and lunatics."\textsuperscript{225} The state may punish parents or others who abuse or neglect children.\textsuperscript{226} Courts also will appoint guardians when they find that the parents are incapable of making decisions concerning their children, or if the parents' choice conveys a disregard for their child's welfare.\textsuperscript{227} This occurs most often when parents choose unconventional medical care for their children or refuse to consent to ordinary medical care that will save their child's life.\textsuperscript{228}

As discussed above, it is clear that parents may authorize the \textit{nontreatment} of anencephalic newborns. The President's Commission recommended that parents of anencephalic infants be authorized to reject "clearly futile therapies" for their newborns.\textsuperscript{229} In addition, the 1984 amendments to the federal Child Abuse Prevention and Treatment Act\textsuperscript{230} provide three exceptions to the Act's prohibition against withholding medically indicated treatment from handicapped infants, all of which apply to anencephalic infants. The Act sanctions nontreatment of handicapped infants if:

\begin{enumerate}
  \item the infant is chronically and irreversibly comatose;
  \item the provision of such treatment would
    \begin{enumerate}
      \item merely prolong dying,
      \item not be effective in ameliorating or correcting all of
            the infant's life-threatening conditions, or
      \item otherwise be futile in terms of the survival of the
    \end{enumerate}
\end{enumerate}

\begin{footnotes}
224. \textit{See generally} Note, \textit{Life-Prolonging}, supra note 190, at 686-90 (providing an overview of the \textit{parens patriae} doctrine).
226. \textit{DECIDING TO FOREGO TREATMENT}, supra note 183, at 212; \textit{see} Note, \textit{Life-Prolonging}, supra note 199, at 683.
227. \textit{DECIDING TO FOREGO TREATMENT}, supra note 183, at 213; \textit{Note, Life-Prolonging}, supra note 199, at 689.
228. \textit{DECIDING TO FOREGO TREATMENT}, supra note 183, at 213-14 n.67.
229. \textit{See id.} at 219.
\end{footnotes}
infant; or
(C) the provision of such treatment would be virtually futile
in terms of the survival of the infant and the treatment itself
under such circumstances would be inhumane. 231

The relevant interest of parents here, however, is to shorten or prolong their infants’ lives in order to obtain the infants’ organs for transplantation. 232 There is no legal authority that supports the parents’ autonomy in this situation. 233 But there are several ways that the state could intervene if parents attempted to authorize organ procurement from their infants: including through the criminal law system, the federal regulations governing research involving children, and common law standards for organ donations by minors.

1. The Criminal Law System

Parents and surgeons could be prosecuted for criminal homicide and assault for obtaining organs from anencephalic infants. First, surgeons who hasten an anencephalic’s death or remove an anencephalic’s organs before the infant is legally dead, could be prosecuted for murder under the Model Penal Code (MPC) standard. 234 Second, a surgeon who removes organs from an infant after he or she has been artificially maintained and declared brain dead may be prosecuted for murder or manslaughter 235 if the infant did not meet brain death criteria. 236 It is homicide to kill a

232. The President’s Commission did recommend that physicians respect parents’ request for futile treatments if they do not cause suffering. But generally, the parents’ intentions are to prolong their infants’ lives and provide “hope against hope,” not to preserve the infants’ organs for donation. See Deciding To Forego Treatment, supra note 183, at 219-20.
233. Parents who do not consent to any methods that would enable organ donation obviously have different interests, but they are not part of this controversy since their wishes are always respected.
234. Model Penal Code § 210.2(1) (1985). Under the MPC, murder is a killing committed “purposely or knowingly” or “recklessly under circumstances manifesting extreme indifference to the value of human life.” Id. State statutes may vary from the MPC standard.
235. The Model Penal Code defines manslaughter as criminal homicide “committed recklessly.” Id. at § 210.3. Again, state statutes may vary.
236. A physician is being criminally investigated in Britain for allegedly removing organs from an anencephalic before the infant was legally dead. Comment, supra note 84, at 452 n.24 (citing Vines, Row Over Anencephalic Babies Reaches Britain, 115 New Scientist 17 (1987)).
person who is already dying, to hasten death, or to kill a "worthless" victim. However, evidence showing the defendant believed his or her conduct was morally justified is among the mitigating circumstances recognized for homicide in the MPC. Third, it is possible that surgeons could be prosecuted for simple or aggravated assault under the MPC if they remove an infant’s organs, close the wound, and allow the infant to die naturally.

Parents could be prosecuted along with the surgeons. Under the MPC, they could be prosecuted as accomplices if they promote or facilitate the surgeon’s crime. Alternatively, they could be prosecuted for the lesser crime of solicitation if they commanded, encouraged or requested the specific criminal conduct.

Parents also could be criminally prosecuted under state child-abuse laws for authorizing any of the methods that enable organ procurement from their infants.

2. Federal Research Regulations

Through federal regulations that govern research, the government may override parents’ wishes to place their anencephalic infants in ventilation programs such as Loma Linda’s. These programs would probably be considered research because

237. W. LaFave & A. Scott, Jr., supra note 79, at § 7.1(d).
238. The MPC advises courts to consider mitigating circumstances including whether “the murder was committed under circumstances which the defendant believed to provide a moral justification or extenuation for his conduct.” MODEL PENAL CODE § 210.6 (4)(d) (1985).
239. Surgeons could be charged with simple assault under the Model Penal Code for “attempt[ing] to cause or purposely, knowingly or recklessly caus[ing] bodily injury to another” or “negligently caus[ing] bodily injury to another with a deadly weapon.” Id. at § 211.1.(1)(a), (b). They also could be charged with aggravated assault for “attempt[ing] to cause serious bodily injury to another, or caus[ing] such injury purposely, knowingly or recklessly under circumstances manifesting extreme indifference to the value of human life,” or “attempt[ing] to cause or purposely or knowingly caus[ing] [such injury] with a deadly weapon.” Id. at § 211.1.(2)(a),(b); see Fost, supra note 122, at 8 (noting that “in such a case, killing would not be the proper term; battery, not homicide, might be the charge.”).
241. Id. at § 5.02.
243. The immediate procurement approach most likely would not be considered “research” because it has been proven effective. West German surgeons who have employed the active-killing method call their procedure an “innovative treatment” rather than fetal research. Kidney Transplantation, supra note 93, at 1069.
anencephalic infants are rarely placed on life-support systems, and critical information is needed on topics such as the effect of respirator support, the reliability of determining brain death in infants, and the ability of infants to feel pain.

Research that directly benefits children is generally considered justifiable. But troubling questions arise when research will not help the subject even though the research may advance scientific knowledge or may benefit other children. Children's inability to consent is the underlying problem. The first principle of the 1949 Nuremberg Code implicitly prohibits involving children in research: "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have the legal capacity to give consent. . . ." The Declaration of Helsinki, published in 1964 by the World Medical Association, is more liberal. It provides that "if [the subject] is legally incompetent the consent of the legal guardian should be secured" for nontherapeutic research. The Declaration was generally accepted in the United States, resulting in the existing practice of obtaining third-party permission, or "proxy consent," for research that does not directly benefit an incompetent subject.

Federal regulations were not clear on the issue of consent for nontherapeutic research, however. But the issue was resolved by the National Commission for the Protection of Human Subjects of Biomedical or Behavioral Research (National Commission), established in 1974 to "identify the requirements for informed consent to participation in . . . research by children, prisoners, and

244. Annas, supra note 3, at 37.
245. Id.; see also The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, 2-4, 4 (1978) (discussing the distinction between practice and research and stating that "the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects").
247. Id.
250. Id.
251. Id.
252. See id. at 93-94 (reviewing inadequate Department of Health, Education and Welfare policy and regulations).
the institutionalized mentally infirm."\textsuperscript{253}

Based on the National Commission's recommendations,\textsuperscript{254} the Department of Health and Human Services (HHS) published regulations in 1983 providing "additional protections for children involved as subjects in research."\textsuperscript{255} These regulations formally govern only federally funded research;\textsuperscript{256} their sanction is the loss of federal funds to the research institution.\textsuperscript{257} But they serve as a national standard that many institutions apply to all research.\textsuperscript{258}

The regulations divide research into four classes, depending on the risks and benefits involved. Three classes could apply here. Though informed parental consent is required for each of these provisions,\textsuperscript{259} consent alone is never sufficient to authorize research. At the very least, institutional review boards (IRBs)\textsuperscript{260} must first determine which classification covers the research before the parents' consent is operative.

Section 46.404 allows research that the IRB finds does not involve "greater than minimal risk."\textsuperscript{261} Minimal risks are defined as "risks of harm anticipated in the proposed research . . . not greater . . . than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests."\textsuperscript{262} The risk posed by organ procurement from anencephalic infants could be determined minimal because the infants have no interests.

Under some circumstances, Section 46.406 approves research in which the IRB determines there is no direct benefit to the subject and a "minor increase over minimal risk,"\textsuperscript{263} but which promises "generalizable knowledge" about the subjects' condition that is of "vital importance for the understanding or amelioration of the subjects' disorder or condition."\textsuperscript{264} This section also requires

\begin{footnotesize}
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\item \textsuperscript{253} R. LEVINE, supra note 248, at 235.
\item \textsuperscript{254} Id. at 235-36.
\item \textsuperscript{255} Additional Protections for Children Involved as Subjects in Research, 45 C.F.R. §§ 46.401-46.409 (1988).
\item \textsuperscript{256} Id. at § 46.101.
\item \textsuperscript{257} Id. at § 46.123.
\item \textsuperscript{258} Walters & Ashwal, supra note 16, at 26.
\item \textsuperscript{259} 45 C.F.R. §§ 46.116, 46.408(b) (1988).
\item \textsuperscript{260} Institutional review boards are established at each individual institution where research is being conducted to review and approve of the research and enforce the criteria of the federal regulations. See 45 C.F.R. §§ 46.103-46.115 (1988).
\item \textsuperscript{261} Id. at § 46.404.
\item \textsuperscript{262} Id. at § 46.102(g).
\item \textsuperscript{263} Id. at § 46.406(a).
\item \textsuperscript{264} Id. at § 46.406(c).
\end{itemize}
\end{footnotesize}
that the project present experiences "reasonably commensurate" with the subject's actual or expected situation.265 "Minor increase over minimal risk" is not defined.266 This provision also could be applied, since the risk could be viewed as a minor increase over minimal risk and the research would provide knowledge about anencephaly that is important for understanding (if not amelioration) of the condition.

When certain conditions are met, section 46.407 allows research that the IRB will not approve under the previous sections.267 First, the IRB must determine that "the research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children."268 In addition, the Secretary of Health and Human Services, after consulting an expert panel and opening the proposal to public review and comment, must agree with the IRB's conclusion and make other findings, including that "[t]he research will be conducted in accordance with sound ethical principles."269 For example, the National Commission permits research to develop a safe and effective vaccine which is justified by the threat of an epidemic.270 This provision could allow approval of the research even if the risk of prolonged survival or suffering was great, because the research is sure to alleviate many serious health problems of children as long as it is conducted ethically.

Thus, if the IRB determines that ventilation programs fall into one of these three categories, it may allow the research upon parental consent. If it determines that none apply, the regulations may prevent the IRB from allowing anencephalic infant participation — even if the parents consent.

3. Common Law Standards For Organ Donations By Minors

Courts have not considered whether parents may authorize

265. Id. at § 46.406(b). This situation includes the subject's "medical, dental, psychological, social or educational" status. Id. at § 46.406 (b).
266. The National Commission provided some guidance, however. It recommended that IRBs estimate risk from at least four perspectives: a common-sense estimation of the risk or estimates of risk based on the results of similar procedures; any statistical information available; and the proposed subject's situation. RESEARCH REPORT, supra note 215, at 8-9.
268. Id. at § 46.407(a).
269. Id. at § 46.407(b).
270. RESEARCH REPORT, supra note 215, at 127.
the shortening or prolonging of their child's life for the sake of another. However, an analogous situation is presented in cases where parents wish to donate the organs of one of their living children for the benefit of another, often a brother or sister.

In the leading case in the area, *Bonner v. Moran*, while the court did not discern when parental consent is *sufficient* to authorize such procedures, the court did hold that parental consent is *necessary* when a minor receives no direct benefit from medical procedures. A fifteen-year-old boy had agreed to undergo several skin-grafting operations at his aunt's request to provide transplants for his severely burned cousin. The boy missed two months of school, suffered substantial pain, was subjected to the risks of anesthesia, and suffered permanent disfigurement. His mother did not know of the first operation.

A Connecticut court did speak to the sufficiency issue however. It held that under its equitable powers, it could permit parents to authorize donations by one child for another, but if the circumstances reflected some benefit to the donor and donee, minimal risk to the donor, the donor's consent, or harm to the donor if the recipient dies. The court held that parents of twins could consent to the donation of one twin's kidney to the other, but only "after a close, independent and objective investigation of their motivation and reasoning." The court found that a kidney transplant was necessary for the twin's survival, the prognosis was excellent, the risks were negligible for both twins, and the donor twin would benefit from saving her sister's life.

In contrast, a Louisiana court held that neither parents nor the courts could authorize surgery to enable a mentally retarded teenage boy to donate a kidney to his adult sister. Though the court found "no doubt that . . . a kidney transplant would be more beneficial to [his sister] than any other known remedy," it was not an "absolute immediate necessity" because dialysis could

271. 126 F.2d 121 (D.C. Cir. 1941).
272. *Id.* at 123.
273. *Id.* at 121.
274. *Id.* at 123.
275. *Id.* at 121.
277. *Id.* at 375, 289 A.2d at 390.
278. *Id.* at 377-78, 289 A.2d at 390-91.
preserve her life. The court rejected the argument that the transplant was in the boy's best interest because his sister would be able to take care of the disabled boy when his parents died. The court concluded that the surgery and loss of a kidney "clearly" would be against the boy's best interest.

Obviously, the anencephalic infant donor is easily distinguished from these donors: the infants lack any interests and are certain to die regardless of the donation. Courts may sympathize with the parents' wishes and permit them to authorize donation — notwithstanding possible violations of criminal laws and federal research regulations. The benefit to the donee is clear, and the court may find the benefit to the donor irrelevant and the risk minimal because of the infant's lack of awareness and certain death. Nevertheless, this line of authority shows that although parental consent is essential for nontherapeutic interventions, it is not necessarily sufficient. Courts will assert their power to review these parental decisions.

Thus, it is clear that parents could refuse to allow donation of their anencephalic infants' organs and authorize nontreatment as part of their parental rights. But their consent does not provide a sufficient basis for allowing donation. The state could intervene through its laws, regulations or courts. Because the usual standards have not been applied to this situation, state intervention will depend on societal interests.

C. Society's Interests

1. Immediate Procurement Approach

Proponents of the immediate procurement approach believe that the societal interest in the benefits of anencephalic organ donation outweigh all other interests. Removing the infants' organs immediately, they argue, will save countless lives and respect the wishes of the infants' parents without harming the infants, who

280. Id. at 187.
281. Id.
282. Id. The court analogized the situation to donation of a minor's property. It found:
Since our law affords this unqualified protection against intrusion into a comparatively mere property right, it is inconceivable to us that it affords less protection to a minor's right to be free in his person from bodily intrusion to the extent of loss of an organ unless such loss be in the best interest of the minor.
Id.
have no potential for awareness in their short lives. Some proponents believe that the infants are not persons.\textsuperscript{283} The Michigan Transplant Policy Center articulates the utilitarian rationale behind this approach: "[O]ne would need to be intoxicated by abstract principle to refuse to seek to do the good that can be done."\textsuperscript{284} Fletcher, Harrison and Robertson observe: "It may be that a majority of the community would give a higher priority to the life of persons needing transplants than to symbolic commitments that do not directly protect other persons."\textsuperscript{285} And Caplan calls it "hollow sentimentality to prohibit such gifts on the grounds that it is repugnant to certain sensibilities to do so."\textsuperscript{286}

Critics of the immediate procurement approach argue that whatever constitutes personhood, anencephalic infants are living human beings; they may be dying, but they are not dead. The interest of society in respect for human life is stronger than its interest in the unknown benefits of anencephalic organ donation.\textsuperscript{287} First, they argue, the law should preserve its commitment to human life by maintaining a clear and consensual definition of death and a firm standard against killing.\textsuperscript{288} Brain death is presently considered a valid standard for determining death.\textsuperscript{289} Redefining death would create confusion and call into question the validity of brain death criteria: Is society manipulating this most fundamental concept to serve its immediate social needs? Is brain death a new definition of death or simply another criteria for determining death? Is there a true definition of death at all, or is death merely a social construct? Regardless of the answers to these questions, many would not easily label infants who breathe on their own, yawn and suck, as dead in order to permit removal of their organs.

A second concern buttressing the respect-for-life interest is that the immediate procurement approach may lead to the use of patients with similar disorders or no consciousness as involuntary donors.\textsuperscript{280} This slippery slope argument, however, is not enough to

\begin{footnotesize}
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\item \textsuperscript{283} See supra notes 101-02 & 144 and accompanying text.
\item \textsuperscript{284} Transplant Policy Center, supra note 36, at 29.
\item \textsuperscript{285} Sources, supra note 2, at 158.
\item \textsuperscript{286} Caplan, supra note 23, at 138.
\item \textsuperscript{287} See supra notes 169-79 and accompanying text.
\item \textsuperscript{288} See supra text accompanying notes 145-46.
\item \textsuperscript{289} See supra notes 71-87 and accompanying text.
\item \textsuperscript{290} See supra notes 149-53 and accompanying text.
\end{enumerate}
\end{footnotesize}
reject this approach. As one commentator notes, "Everything leads to something, often something bad." Legislation could alleviate this danger by either explicitly limiting its application to anencephalic infants or requiring complete cortical death. But the concern is valid. Such legislation could in fact lead to the brutalization and desensitization of the medical community and undermine the public's trust in transplantation and the organ donor system. There also is a history of misdiagnosis with anencephaly. And future developments may complicate the problem. For example, what if physicians someday can diagnosis permanent coma with the same certainty as anencephaly? Would these patients then be subject to forced organ donations?

A final question that tilts the scale in favor of the respect-for-life interest for critics of the immediate procurement approach is: Is the need for infant organs great enough to justify such extreme measures? Opponents of this approach maintain that there is not enough evidence to show that anencephalic organ donation will be successful enough to warrant making exceptions to such fundamental legislation as that concerning death.

2. The Intervention Approach

Critics of the intervention approach also argue that society's interest in respect for persons outweighs its interest in the benefits of obtaining anencephalic organs. Perhaps their strongest argument is that it is wrong to use the infants as a means to an end. Doctors Fletcher, Robertson and Harrison respond that this prohibition fails to apply to the cooling method. Instead, it is morally legitimate according to the double effect theory. Under this theory, three criteria are weighed to determine if causing an evil effect to create a good effect is justifiable. First, the actor must not

291. Fost, supra note 122, at 8.
292. Id.
293. See supra notes 109 and accompanying text.
294. Fost, supra note 122, at 8.
295. Id.
296. See supra notes 163-68 and accompanying text.
297. Fost, supra note 122, at 8.
298. See supra notes 169-79 and accompanying text.
299. See, e.g., Annas, supra note 3, at 38.
300. See supra notes 154-57 and accompanying text.
301. Sources, supra note 2, at 158.
302. Id. at 159.
intend to cause the evil effect. Second, the evil must never precipitate the good effect; both effects must occur at the same time. Third, a sufficiently grave reason for the evil effect must exist. According to this theory, physicians who use the cooling method do not intend to cause death but to preserve organs. The hastening of death is an "acknowledged but unintended effect of a primary intent to preserve organs." Second, the preservation of organs and hastening of death occur simultaneously; death does not cause the organs' viability. Finally, saving lives is a sufficiently grave reason to obtain the organs in this way.

Proponents of ventilation programs argue that the intervention approach does not violate Kant's categorical imperative. They point out that philosophers disagree about what Kant meant by persons as ends. One philosopher believes that Kant meant possessors of "good will"; another believes he meant rational beings with autonomous reasoning ability. Neither of these definitions would apply to the anencephalic infant. Others argue that regardless of how the principle is interpreted, Kant most likely did not consider non-self-aware humans, such as anencephalic infants, in his writings. Two commentators conclude that the maxim is a myth, an ideal that supports "our sense of exalted human worth and individual rights" but has limits. They caution that becoming "more enamored with symbolic rather than actual personal life" could lead to "compelling utilitarian claims of a great number of persons who would be moral victims of a thoroughgoing Kantian ethic."

Patients are treated for another's benefit in at least three analogous situations. First, it is standard practice to switch efforts from prolonging life to maintaining viability of organs before brain death. Second, pregnant women who have had traumatic ac-

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303. Id.
304. Id.
305. Id.
306. Id.
307. Id.
308. Id.
310. Id. See also Transplant Policy Center, supra note 36, at 29 (Kant was referring to an "autonomous moral agent, a rational human will" in his categorical imperative).
312. Id.
313. Id.
314. Id. at 23.
cidents are placed on respirators while still alive for the benefit of their fetuses, and are artificially maintained after brain death until the fetus is viable. Third, dying newborns are often kept alive until relatives can see them.  

V. A MIDDLE GROUND

At this time, the threat that the immediate procurement approach poses to the societal interest in respect for human life outweighs the uncertain benefits of obtaining these infants' organs. Amending legislation that defines a social concept as fundamental as death would be dangerous and premature for it may sweep in other patients with similar disorders, and lead to desensitization of the medical community.

The societal interest in the enormous potential of the ventilation programs far outweighs the abstract, Kantian respect-for-life concerns used to oppose them. In the context of research, the National Commission wrote that a "child involved in research may be used as a means, but not merely as a means; for no investigator is free to use a child in any way he wishes." It found the important question was whether the treatment itself, or how the children are used, is immoral.

Some critics of the ventilation programs claim the intervention is futile and inhumane. Their most concrete objection is that the programs prolong the infants' dying process or long-term survival and possibly expose them to pain or premature organ procurement. However, futile treatment is not necessarily inhumane. Physicians may establish that interventions do not expose the infants to pain or undignified handling, promote long-term survival, or allow premature organ procurement. If so, there would be great dignity in saving lives and respecting the urgent wishes of parents.

If society is to realize the benefits of its progress, research and innovation are vital. Doctor Joyce Peabody, Loma Linda's Chief of Neonatology, quoted Kierkegaard in this regard: "Life can only be understood backwards, but it must be lived forwards." However, rather than physicians and institutions going forward with these programs on their own, bodies that represent societal interests — such as Congress, the courts, or the DHHS

315. Id.
317. Id.
ANENCEPHALIC INFANTS AS ORGAN DONORS

— must forge a consensus. This note proposes that ventilator programs such as Loma Linda's should be conducted to enable anencephalic organ donation. However, the programs should include the following safeguards to ensure that the programs are conducted according to sound ethical principles:

1. **Research.** Research is vital to a better understanding of the benefits and risks involved in anencephalic organ donation. More information is needed on such topics as the nature and cause of anencephaly; the long-term effect of respirator support on anencephalic infants; the reliability of determining brain death in the infants; the ability of anencephalic infants to feel pain; the accuracy of diagnosis with anencephaly; and the efficacy of obtaining organs from anencephalic babies, depending on the availability of recipients, the quality of organs obtained, the advancement of pediatric transplantation, and the effect of such programs on health care personnel.

2. **Brain Death Determination.** Valid criteria for determining brain death in these infants must be established and rigorously followed.

3. **Time Limits on Respirators.** Limits must be placed on the time infants are attached to respirators to ensure the ventilation does not overly prolong the infants' dying process or promote their long-term survival.

4. **Parental Consent.** Informed consent must be carefully obtained and fully documented. Safeguards must be established to prevent any manipulation of the parents' plans.

5. **Treatment of Infants.** Steps must be taken to ensure that the infants do not experience any pain and are always treated with dignity.

6. **Cost.** The cost of the programs must be considered in light of the competing demands for other types of health care and research for children.

If these programs prove medically unsuccessful, the immediate procurement approach should be reexamined in light of the data collected from the research. At that time, it may be possible to determine, for example, if there is evidence to support the efficacy of anencephalic organ donation; if the “donation” could be carried out in an ethically sound manner; and if the law and society were willing to be vigilant against the expansion of involuntary donation into other groups of patients.
CONCLUSION

The controversy waged over anencephalic organ donation will not easily be resolved; persuasive arguments abound but medical knowledge and legal precedent remain scant. Nevertheless, a consensus must be reached. Ultimately, this consensus will reflect how society balances its interests in the potential benefit of anencephalic organ donation against respect for human life. This Note proposes that these interests can best be balanced through the use of ventilation programs — a middle ground that fosters both hope and life.

Beth Brandon