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THE LEGAL, ETHICAL, AND MEDICAL OBJECTIONS TO PROCURING ORGANS FROM ANENCEPHALIC INFANTS

Lisa E. Hanger†

INTRODUCTION

RECENT TECHNOLOGICAL ADVANCES HAVE made pediatric organ transplantation possible in infants. Technology has provided the means by which the medical profession may artificially sustain life to prolong an infant’s dying process, or to preserve organs for later transplantation. Amidst the emotional controversies over abortion, the right to life, and the "right to die," it has been debated whether the 1000 to 2000 anencephalic infants born annually in the United States¹ should become organ donors prior to their natural deaths. Many parents, physicians, ethicists, and politicians have targeted anencephalic infants as a potential solution to the problem of pediatric organ shortages.² Proponents argue that

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¹. Committee on Bioethics, Infants With Anencephaly as Organ Sources: Ethical Considerations, 89 Pediatrics 1116, 1116 (1992). Even eight years ago, statistics showed that up to 3000 anencephalic infants were born annually with 1 in every 1000 births. See Alexander M. Capron, Anencephalic Donors: Separate the Dead from the Dying, Hastings Center Rep., Feb. 1987, at 5 (stating that according to Godfrey Oakley of the Centers of Disease Control, between 2000 and 3000 anencephalic infants are born each year). However, in the past few years, as many as 95% of anencephalic infants have been aborted upon early diagnosis during pregnancy. Frank A. Chervenak & Margaret A. Farley et al., When Is Termination of Pregnancy During the Third Trimester Morally Justifiable?, 310 New Eng. J. Med. 501, 501 (1984) (stating that anencephaly is one of the few conditions in which an abortion may be performed even during the third trimester); D. Alan Shewmon et al., The Use of Anencephalic Infants as Organ Sources, A Critique, 261 JAMA 1773, 1774 (1989) (stating that 95% of anencephalic infants are electively aborted).

². Id.
the vitality of the anencephalic infants’ organs, the certainty of imminent death, and the desire of parents to save the life of another child make anencephalic infants ideal organ donors.\(^3\) While use of anencephalic infants may seem like a simple solution to the short supply of pediatric organs, it poses many legal, ethical, and medical problems. Because of these concerns, no bill has been enacted on either the federal or state level authorizing anencephalic infants to become live organ donors under any circumstances.\(^4\) For the most part, the medical profession favors preserving the sanctity of human life. Most doctors prescribe treating anencephalic infants with “comfort care”\(^5\) for the duration of their lives, allowing family members to donate the infants’ organs at the time of natural death.\(^6\)

This Note will outline the legal, ethical, and medical concerns associated with procuring organs from live anencephalic infants. Part I will provide a brief definition of anencephaly. Part II will discuss the legal and ethical ramifications of extracting human organs before natural death. Part III will ex-

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3. See, e.g., Jay A. Friedman, Taking the Camel by the Nose: The Anencephalic as a Source of Pediatric Organ Transplants, 90 COLUM. L. REV. 917, 921-22 (1990) (stating that anencephalic infants are particularly ideal organ donors because their organs, other than the brain, develop normally); Joyce L. Peabody et al., Experience With Anencephalic Infants as Prospective Organ Donors, 321 NEW ENGL. J. MED. 344, 344 (1989) (stating that the certainty of death, accuracy of diagnosis, and desires of parents in assisting children in need of organ transplants have made anencephalic infants attractive as potential sources of pediatric organs). The American Medical Association also has endorsed organ donations from anencephalic infants. See Council on Ethical and Judicial Affairs, American Medical Assoc., “The Use of Anencephalic Neonates as Organ Donors,” 273 JAMA 1614 (1995).


5. The generally accepted medical standard of care requires that anencephalic infants be treated with the “comfort care” of warmth, nutrition, and hydration until death occurs naturally. It is not required that anencephalic infants be provided aggressive treatment to extend their lives based upon their underlying neural defect since the defect is incurable and treatment is medically futile. See President’s Comm’n For The Study of Ethical Problems on Medicine & Biomed. & Behavioral Research, Deciding To Forego Life-Sustaining Treatment: A Report On The Ethical, Medical, and Legal Issues In Treatment Decisions (1983) [hereinafter President’s Comm’n, Forego Life-Sustaining Treatment] (finding that it is in the infant’s best interests to withhold “clearly futile treatment”). In re Baby “K” (Three Cases), 16 F.3d 590, 596 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994); see also James W. Walter & Stephen Ashwal, Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues, 18 HASTINGS CENTER REP., OCT.-NOV. 1988, at 19.

amine four medical proposals for preserving the bodies of anencephalic infants in an attempt to prevent organ deterioration before transplantation, and will discuss the medical obstacles to anencephalic infants becoming feasible organ donors.

I. THE DEFINITION OF ANENCEPHALY

Anencephaly is a serious congenital defect of unknown cause in which infants are born without a cerebral cortex and often without a cranium. They are born with only a brain stem, restricting mobility to only the limited functions of the autonomic nervous system, including breathing, digestion, circulation, sucking, swallowing, crying, and reflexively responding to stimuli. Since anencephalic infants lack their cerebral hemispheres, they are incapable of consciously sensing pain or achieving any higher brain activity as cognitive thought. Most anencephalic infants have a very short life span of hours, days, or just a few weeks. Few survive beyond the first year. 7 Forty percent of anencephalic infants are stillborn, and of the remainder, 65% die during the first day of life, 30% die by the end of the first week, and only 1.5% live as long as one month. 8 Quite obviously, anencephalic infants are extremely debilitated and they exist in a permanently unconscious and vegetative state. However, since they are able to sustain respiration and heartbeat without medical intervention, these infants are not considered “dead” or even “brain dead” under current legal and medical standards. 9 Rather, even with their objectively low


8. P.A. Baird & A.D. Sadovnick, Survival in Infants with Anencephaly, 23 CLINICAL PEDIATRICS 268, 270 (1984); see The Anencephalic as a Source for Pediatric Organ Transplants: A Question of Medical Ethics: Hearings on Cal. S. 2018 Before the Cal. Legislative Senate Subcomm. on the Rights of the Disabled 9, 64 (1986) [hereinafter Subcommittee Hearings] (providing the testimony of Leslie Rothenberg, Adjunct Assistant Professor of Medicine, and Director, Program in Medical Ethics, UCLA Medical Center). Cases of unusually long survival are often erroneously diagnosed as anencephaly. Medical Task Force on Anencephaly, The Infant with Anencephaly, 322 NEW ENG. J. MED. 669, 671 (1990) [hereinafter Medical Task Force]. See also Friedman, supra note 3, at 922.

quality of life, anencephalic infants are living, breathing human beings, deserving of comfort, respect, and bodily integrity.

II. LEGAL AND ETHICAL OBJECTIONS TO ORGAN PROCUREMENT FROM LIVE ANENCEPHALIC INFANTS

Historically, lay and medical communities have forbidden individuals to donate or sell their body parts while still alive. Individuals are only legally authorized to donate one of their paired organs, such as a kidney or lung to a needy recipient in order to prevent the sale of organs or the exploitation of donors. In most instances of organ donation, a physician will seek a family's consent to donate a loved one's organs before or at the time of death. The physician will then contact the local organization coordinating organ transplantations to arrange the logistics of extracting the organs, and assessing their suitability of use. If the organs are designated healthy, all usable organs are procured immediately upon death. The entire organ selection process takes just a few hours since organs begin to quickly deteriorate following natural death due to oxygen-deprivation. This problem of the physiological deterioration of or-


10. See Sharon Nan Perley, From Control Over One's Body To Control Over One's Body Parts: Extending the Doctrine of Informed Consent, 67 N.Y.U. L. REV. 335, 337 (discussing a patient's dignitary interest in her excised tissues, cells, and body parts for medical research and use).


12. See, e.g., Beth Brandon, Anencephalic Infants as Organ Donors: A Question of Life or Death, 40 CASE W. RES. L. REV. 781, 792 (1990); Donald N. Medearis, Jr. & Lewis B. Holmes, On the Use of Anencephalic Infants as Organ Donors, 321 NEW ENG. J. MED. 391, 391-93 (1989) (referring to the limited availability of healthy organs from anencephalic infants); Medical Task Force, supra note 8, at 670; Michael R. Harrison, The Anencephalic Newborn as Organ Donor, HASTINGS CENTER REP., Apr. 1986, at 21.
gans has prompted discussion about expanding the traditional, legal definition of death to include anencephalic infants so that their organs may be procured while the infants are still alive. The proposal, however, raises a number of legal and ethical concerns about the definitions of "life," and "death," and society's willingness to procure the organs of one individual before death solely for the benefit of other persons.

A. The Current Statutory Definition of Death

In the United States, the Uniform Anatomical Gift Act (UAGA) requires that an individual be dead before his or her organs may be procured. Section 1(1) clearly states that "anatomic gifts can be made only after the donor has been declared dead." The Uniform Determination of Death Act (UDDA) defines death as either (1) the irreversible cessation of heart rate and respiration or (2) total brain death. Since anencephalic infants maintain both a heartbeat and respiration without medical assistance, they do not fit the first prong of the UDDA, the traditional cardio-respiratory medical definition of death. Furthermore, since they have active brain stems, neither do they satisfy the UDDA's second prong of whole brain death. As a result, in recent years, it has been proposed that

13. See supra note 12 and accompanying text.
15. The UDDA was adopted in 1981 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and provides that "[a]n 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." UDDA § 1, 12 U.L.A. 386 (1980 & Supp. 1993). Like the UAGA, the UDDA has been adopted in all 50 states and the District of Columbia. See Arras & Shinnar, supra note 9, at 2285; Brandon, supra note 12, at 792. The UDDA has replaced the "Harvard Criteria" developed in the Harvard Committee Report of 1968 as an alternative definition of death for an individual artificially sustained by life support mechanisms. The Harvard Committee identified four criteria: 1) unreceptivity and unresponsivity; 2) no movement or breathing; 3) no reflexes; and 4) a flat electroencephalogram. Harvard Committee Report of 1968, supra note 9, at 339. See also President's Comm'n, Deciding to Forego Treatment, supra note 5 (establishing whole brain death as a solid objective standard for defining death on which physicians and philosophers could agree).
16. President's Comm'n, Defining Death, supra note 9; Arras & Shinnar, supra note 9, at 2285; Peabody et al., supra note 3, at 344.
the UDDA be amended to create a third category specifically classifying anencephalic infants as "dead."

B. Legal and Ethical Problems with Amending the Uniform Determination of Death Act

Some bioethicists have argued that the Uniform Determination of Death Act should be amended to declare anencephalic infants legally dead immediately upon the medical diagnosis of anencephaly. Such an amendment would enable organ procurement without the UDDA requirement of cardio-respiratory death or total brain death. In 1986, State Senator Milton Marks proposed an amendment to the California state legislature that stated "an individual born with the condition of anencephaly is dead." The proposal failed and he later revised its language after receiving sharp criticism for introducing such a radical change in the definition of death and violating the spirit of the UDDA.

Amidst this country's ongoing philosophical struggle with the concepts of life and death reflected in the abortion debate, society does not seem equipped to change an already vague concept of death to include a group of individuals who are still living, breathing human beings. While, theoretically, it may be easier for people to conceive that a baby born without much of its brain is not really "alive," many people are not convinced that a tiny baby with its eyes open and heart beating is already

17. See, e.g., Robert D. Truog & John C. Fletcher, Anencephalic Newborns: Can Organs Be Transplanted Before Brain Death?, 321 NEW ENG. J. MED. 388, 388 (1989) (encouraging the use of anencephalic organs as soon as the diagnosis of anencephaly is confirmed).

18. Id. But see Capron, supra note 1, at 6. Capron, an opponent of anencephalic organ procurement suggests that death is a single concept, not a two-part definition as the UDDA suggests. He asserts that anencephalic infants are alive so they do not meet the traditional cardiovascular definition of death or whole brain death. Id.


20. Capron, supra note 1, at 6 (stating that adding anencephalic infants to the definition of death would "radically change" the social and medical understanding and practices surrounding death). See generally Brandon, supra note 12, at 799-800 (stating that changes in the UDDA would represent a marked departure from the legal and social concepts of life and death, which would not be tolerated by society).
dead.\textsuperscript{21} First, concluding that an individual with a spontaneous heartbeat and respiration is "dead" would render the traditional cardio-pulmonary definition of death incorrect.\textsuperscript{22} Secondly, declaring anencephalic infants as "so close" to death to be considered legally dead merely to increase the organ donor pool, raises a number of important ethical objections. When the Task Force on Death and Dying of the Institute of Society, Ethics, and the Life Sciences analyzed proposals to change the Harvard Criteria of death, they rejected this rationale as an inappropriate and unjustifiable means for combating the shortage of pediatric organs in this country.\textsuperscript{23} In reaching their conclusion, the Task Force was concerned about the following: (1) reference to anencephalic infants being "brain absent" or lacking "personhood," (2) emphasis on the quality of life over the sanctity of life, and (3) the slippery slope effect.

1. The Concept of "Personhood"

Proponents of amending the UDDA advocate creating a separate category for anencephalic infants because the infants are "brain absent" and lack higher-brain activity, the key aspect of personhood.\textsuperscript{24} Those who support this position argue that the definition of whole brain death revolves around this concept of "higher-brain" death, or "cortical death."\textsuperscript{25} Since anencephalic infants do not possess a cerebral cortex, it is argued that they are "brain-absent" and should not be given the same moral value as other human beings.\textsuperscript{26} Since higher-brain

\textsuperscript{21} A visual inspection of an anencephalic infant's movements and reactions illustrate that the child is not "dead." See Koenig, supra note 7, at 449. As Beth Brandon has stated, "[d]ying anencephalic infants are just that, dying: they are not dead." Brandon, supra note 12, at 800.

\textsuperscript{22} The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research rejected such a notion. See President's Comm'n, Forego Life-Sustaining Treatment, supra note 5; see also Brandon, supra note 12, at 800.

\textsuperscript{23} The Task Force, upon evaluation of changing the definition of death based on a need for organs, determined that the criteria for pronouncing an individual dead should be completely independent of whether that person is an organ donor. Report of the Task Force, supra note 9, at 299-300. See also Brandon, supra note 12, at 790 n.75.

\textsuperscript{24} See, e.g., Committee on Bioethics, supra note 1, at 1118; Koenig, supra note 7, at 446; Medearis & Holmes, supra note 12, at 392.


\textsuperscript{26} See Committee on Bioethics, supra note 1, at 1118.
functioning distinguishes humans from other species, an “irreversible absence of cognitive function” represents the “absence of personhood.” It is also argued that because anencephalic infants are not able to perform upper brain activities, such as thinking, memory, affectivity, or consciousness, they should not be afforded the same protection under the law as other human beings. This line of reasoning is founded on the concept that “all rights enumerated in the Constitution and the Bill of Rights are predicated on consciousness, or the capacity of consciousness, except for the right to life itself, which becomes meaningless when consciousness can never exist, as in an anencephalic infant.” Thus, the argument goes, since anencephalic infants are “nonpersons,” harming, wronging, or using their organs before their natural death would not violate any legal or ethical principle.

This point of view, however, overlooks the important fact that anencephalic infants are not “brain-absent.” Since these infants possess a functional brain stem, their brain is not completely “absent.” Yet, it is argued that since these infants lack “personhood,” they have no right to life. However, if these infants lack personhood, then, under this rationale, many other groups of individuals who are mentally debilitated or terminally ill would fall under this category and be subject to the involuntary procurement of their organs as well. Clearly, such a thought reflects a devaluation of life. Objectively, observation shows that anencephalic infants possess “a remarkable hetero-


29. See, e.g., Cranford & Smith, supra note 27, at 247.

30. Churchill & Pinkus, supra note 25, at 160. Some even go so far as to say that since the infant cannot consciously feel and is not “alive,” “killing is therefore not an issue.” Trugg & Fletcher, supra note 17, at 390. See also Shewmon et al., supra note 1, at 1775.

31. Arras & Shinnar, supra note 9, at 2284; Shewmon, et al., supra note 1, at 1775 (contending that to harvest organs from anencephalic infants is to assert the philosophical tenet that anencephalics are not human beings).

32. Shewmon et al., supra note 1, at 1775 (stating that such groups might include terminally ill patients, death row inmates, and infants with fatal congenital diseases); see infra notes 34-35 and accompanying text.
geneity of morphologic and functional features" that render
them a group of "persons" sharing like characteristics and
traits. Furthermore, although the definition of "personhood"
has not been fully resolved legally or philosophically, all indi-
viduals born alive are currently considered "persons" under the
law, including anencephalic infants. Only human embryos and
fetuses are not considered legal "persons" and do not receive
the protection of constitutional rights.

2. Quality of Life versus Sanctity of Life

Closely related to the debate about personhood is the be-
lief that since anencephalic infants possess no ability to think
or feel, they have an extremely low quality of life that is not
worth preserving or respecting. Ironically, both proponents and
opponents of anencephalic infant organ donations place great
value on the concept of "saving life." Individuals who argue
that anencephalic infants should be considered "dead" desire to
save the lives of children awaiting organ transplants, while op-
ponents ground their beliefs on saving the lives of the
anencephalic infants themselves. This debate seems to focus on
an argument between those who place value on the "quality" of
life versus those who emphasize the "sanctity" of all life.

Because anencephalic infants will never revive from a per-
manently unconscious state, never communicate with the world,
and never think or speak, some believe they live a low quality
of life that is not even worth living. Yet, observation shows that
these infants, like other infants, sleep, eat, breathe, smile, and
cry. Although such a life invariably fails to meet the subjec-
tive standard of a "high" quality life, it is still a life that should
be protected. Religious and ethical beliefs support the idea that

33. Medearis & Holmes, supra note 12, at 392.
34. No agreement currently exists among philosophers, physicians, or the public as
to what characteristics constitute personhood. This discord is clearly evidenced by the abor-
tion debate, much of which revolves around the concept of whether a fetus should be con-
sidered a "person." Alexander L. Caplan, Should Fetuses or Infants be Utilized as Organ
Donors?, BIOETHICS, Apr. 1987, at 119, 123.
35. See, e.g., Potter, supra note 27, at 41-42 (discussing Roe v. Wade, 410 U.S. 113
(1973), in which the court stated that "the word 'person' as used in the Fourteenth
Amendment does not include the unborn.").
36. See supra note 21. See also Dan Allison, Anencephalic Babies Must Not Die to
Serve Others, ST. PETERSBURG TIMES, May 1, 1992, at 2 (stating that the life of the
anencephalic infant belongs to the infant, "and [is] no one else['s] to take.").
all life should be valued, and that God, fate, or a force other than another human being should determine the precise moment of death. Respect for the symbolic value and dignity of all life imposes moral and legal constraints on the killing of individuals who may be perceived as less significant or less valuable to society. All individuals, no matter how debilitated, have a right to bodily integrity. It is when we as a society begin to draw lines as to which life is subjectively meaningful to society that the worth and value of all human life becomes threatened, and the right to bodily integrity becomes meaningless.

3. Fear of the Slippery Slope

Considering anencephalic infants "dead" or "close enough to death" instills in the public a fear that other individuals very near death also will be declared dead and will be killed for the sake of procuring their organs. If the UAGA or state statutes are amended to require anencephalic infants to become organ donors, it is believed that other individuals with neural tube anomalies or debilitating cognitive deficiencies also may be forced to become organ donors before their natural deaths. Specifically, the "slippery slope" would lead most directly to those infants born with hydroencephaly and microencephaly as becoming forced organ donors. This position could then extend to other groups of people similarly situated who possess only limited cognitive functioning or who arguably lack a "valid" interest in life, including death row inmates, adults in a permanently vegetative state, individuals with Alzheimer's dis-

37. See In re Baby "K," 832 F. Supp. 1022, 1026 (E.D. Va. 1993), aff'd, 16 F.3d 590 (4th Cir.), cert. denied 115 S. Ct. 91 (1994) [hereinafter Baby K] (stating the religious grounds on which Baby K's mother desired not to have her anencephalic child determined "dead" so that her organs could be procured).

38. Arras & Shinnar, supra note 9, at 2285 (hydroencephalic infants and those with other congenital neural anomalies); Committee on Bioethics, supra note 1, at 1118 (permanently unconscious patients); Shewmon et al., supra note 1, at 1775 ("incompetent patients in the final stages of a terminal illness or even prisoners on death row").

39. Hydroencephaly is a congenital neural condition where the cranium becomes filled with fluid during gestation, taking the place of the cerebral hemispheres. THOMAS L. STEDMAN, STEDMAN'S MEDICAL DICTIONARY; A VOCABULARY OF MEDICINE AND ITS ALLIED SOURCES, 964-66 (Jacob A. Stein ed., 1972).

40. Microencephaly is a congenital neural condition whereby the infant is born with a very small head which constrains the growth of the brain. Id.
ease, or incompetent individuals with terminal illnesses. To declare as dead many of these groups whom the general population perceive to be very much alive could jeopardize the ethical integrity of the medical profession and decrease public trust in medicine. Many individuals also would become even more skeptical of organ donation. While some groups have tried to minimize the fear of a slippery slope by arguing that "safeguards" would prevent groups of individuals other than anencephalic infants from being affected by an amendment to the UDDA, any "safeguard" would not be sufficient. Once "very fine distinctions [are made] regarding the dying," the risk of descending down the slippery slope becomes significant.

C. Legal and Ethical Problems with Amending the Uniform Anatomical Gift Act

Besides amending the UDDA, some groups also have proposed amending the Uniform Anatomical Gift Act (UAGA) to allow the organ procurement from anencephalic infants immediately upon birth. The UAGA provides guidelines which allow an individual to make an anatomical gift of his or her own organs or tissue "upon or after death." Since the UAGA provision only applies to competent adults who are able to decide whether to donate their organs and tissue upon death, the UAGA has provided that the "next of kin" have the authority

41. See, e.g., Arras & Shinnar, supra note 9, at 2285 (infants with congenital neural anomalies and those in a permanently vegetative state); Brandon, supra note 12, at 802 (those in a permanently vegetative state, the mentally retarded, or those with Alzheimer's disease); Medearis & Holmes, supra note 12, at 392 (prisoners on death row, incompetent patients in a permanently vegetative state, and those with organ failure); Shewmon et al., supra note 1, at 1775 (terminally ill patients, death row inmates, and infants with fatal congenital illnesses).

42. Botkin, supra note 14, at 254 (expressing concern for the "gradual exploitation" of medicine and society); Diane Gianelli, Calling Anencephalic Donors Dead; Can Anencephalic Infants be Declared Dead at Birth So That Their Organs Can Be Transplanted?, AM. MED. NEWS, June 29, 1992, at 2.

43. Truog & Fletcher, supra note 17, at 390 (stating that some UDDA amendment proposals would specifically exclude hydroencephaly, microencephaly, permanently vegetative state, and various chromosomal abnormalities).

44. Gianelli, supra note 42, at 2.

45. See, e.g., Medearis & Holmes, supra note 12, at 391; Shewmon et al., supra note 1, at 1775.

to determine whether their minor child’s organs may be used for organ donation upon death.\textsuperscript{47}

Under the UAGA, however, organs may not be procured until an anencephalic infant has died.\textsuperscript{48} Those who have proposed that the UAGA be amended want to allow the extraction of hearts, livers, kidneys, and other usable organs from anencephalic infants before death.\textsuperscript{49} Since these infants are alive, however, this proposal would cause the infants essentially to be killed in order to procure their organs. It is argued that the procurement of the organs is justified since the parents’ dignitary interests as the next of kin who wish to donate their child’s organs become frustrated while waiting for the infant to die naturally since the organs deteriorate and become unsuitable for donation.\textsuperscript{50}

There are two major ethical implications with passing an amendment allowing the immediate procurement of organs from anencephalic infants under the UAGA. First, killing a human being who is still alive is considered murder in every state in this country. Second, extracting organs from one human being for another person’s use raises important ethical considerations regarding the use of one individual as the means to an end for another.

1. Killing for the Purpose of Procuring Organs

Advocates of amending the UAGA to allow anencephalic organ donation argue that since anencephalic infants are not “persons,” they are not “alive,”\textsuperscript{51} and therefore they are not really “killed” when their organs are removed. Based upon this reasoning, however, it would follow that other persons exper-

\textsuperscript{47} Section 3(a) of the UAGA provides that decision-making authority for organ donation goes to family members, in the following order: (1) the spouse of the decedent; (2) an adult son or daughter of the decedent; (3) either parent of the decedent; (4) an adult brother or sister of the decedent; (5) a grandparent of the decedent; or (6) the guardian of the person of the decedent at the time of death. Since an infant obviously does not have a spouse or adult son or daughter, the infant’s parents are given priority in consenting to donation of the infant’s organs. UAGA § 3a, 8a U.L.A. 47 (1987 & Supp. 1990).

\textsuperscript{48} See supra notes 14-15 and accompanying text.

\textsuperscript{49} Medearis & Holmes, supra note 12, at 392.

\textsuperscript{50} See, e.g., Brandon, supra note 12, at 787-88 (explaining that parents’ interests are sometimes frustrated by the current state of the law). See also supra note 12 regarding organ deterioration.

\textsuperscript{51} See, e.g., Truog & Fletcher, supra note 17, at 390. See also supra notes 25-35 and accompanying text for a discussion of “personhood.”
iencing severe cognitive disabilities, terminal illness, or imminent death are not truly "alive" either, and thus would not be "killed" if their heart rate and breathing were artifically stopped to procure their organs.  

It is further argued that organs of anencephalic infants should only be removed if the parents' motivations are to help save the lives of other children. Yet, if the desire to act with unselfish charity is a motivator for declaring an anencephalic infant as dead, this argument would logically extend to other groups as well, such as those with hydroencephaly or microencephaly, or those born in a permanent vegetative state. This logic also would include the adult population, who could allow live donors to be killed so that they may charitably "donate" their organs to a needy person. Not only is fear of this slippery slope very real, but the idea of killing a living, breathing human being to procure organs for the purpose of increasing a potentially usable organ pool is immoral and should not be permitted.

2. The Use of Anencephalic Infants as a Means to an End

No group of human beings exists solely to serve the needs of another group. Immanuel Kant's Categorical Imperative "calls for humans to be treated as ends in themselves, and never solely as a means to an end." Those who strongly believe that anencephalic infants are not "humans" also believe that using these infants to benefit other people does not violate Kant's Categorical Imperative since utilitarian theory dictates that society benefits when the greatest good is provided to the greatest number of people. This utilitarian principle, however, violates the medical commitment to preserving life. The first

52. See supra notes 38-42 and accompanying text; Arras & Shinnar, supra note 9, at 2284; see also Brandon, supra note 12, at 802.

53. Koenig, supra note 7, at 472. However, altruism may be mistaken for motivations arising out of "ambivalence, depression, hidden problems, fear, erroneous perceptions, and misconceptions." Churchill & Pinkus, supra note 25, at 156.

54. A number of authors and bioethicists have addressed this issue. Arras & Shinnar, supra note 9, at 2284; Brandon, supra note 12, at 802; see Friedman, supra note 3, at 917; Truog & Fletcher, supra note 17, at 390.

55. In particular, see Truog & Fletcher, supra note 17, at 390 (stating that since the anencephalic infant is not "alive," Kant's dictum is not violated).
and foremost principle of medical ethics is to preserve life.\textsuperscript{56} It should be the continued goal of the medical profession to provide comfort and care to all individuals for the duration of their lives and to protect the personal integrity of their bodies.\textsuperscript{57} Treating anencephalic infants differently from other patients with debilitating conditions because their lives are shorter, and their bodies as mere "receptacles for organs," is not only an unethical violation of the Hippocratic Oath but also a violation of the Americans with Disabilities Act and other moral codes.\textsuperscript{58}

Aside from these two important ethical objections, the donor's dignitary interest in donating the anencephalic infant's organs should be given the same recognition as the interests of other incompetent donors.\textsuperscript{59} Moving the date of procurement from the date of death to the date of birth does not necessarily alleviate the claimed frustrations of the anencephalic infant's next of kin. To have any successful organ transplant, the organs first must be screened and found suitable for an available recipient. Consequently, amending the UAGA invokes concern not only about killing infants while they are still very much alive, but does not resolve the logistical and compatibility problems experienced by all organ donors.

\textsuperscript{56} The medical commitment to preserving life is grounded upon the Hippocratic Oath which every physician swears to follow to become licensed as a medical practitioner. The Hippocratic Oath states, in pertinent part:

\begin{quote}
I swear ... I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrongdoing. ... I will keep pure and holy both my life and my art. ... Into whatsoever house I enter, I will enter to help the sick, and I will abstain from all intentional wrongdoing and harm. ... Now if I carry out this oath, and break it not, may I gain forever reputation among all men for my life and for my art; but if I transgress it and forswear myself, may the opposite befall me.
\end{quote}


\textsuperscript{57} \textit{See} Brandon, \textit{supra} note 12, at 800-01 (discussing the objections to the utilitarian ideas that are commonly cited as justifications for anencephalic organ donations).


\textsuperscript{59} \textit{See} Perley, \textit{supra} note 10, at 348 (stating that all human beings retain a moral, dignitary interest in organs removed from one's body).
D. Recent Common Law Treatment of Anencephalic Infants

Much of the debate over organ procurement is closely related to the standard practice of withholding active or intrusive medical treatment from anencephalic infants. Recent court decisions have supported the belief that the life of an anencephalic infant is sacred and is worthy of protection under the law. Courts have stated, however, that maintaining the life of an anencephalic infant does not warrant application of futile medical treatments, but rather, requires only "comfort care." In the two recent cases of Baby K and Baby Theresa, courts have examined constitutional issues and statutory provisions and determined that the lives of anencephalic infants should be protected by law.


The recent ruling of In re Baby K by the United States Fourth Circuit Court of Appeals, raises issues about three federal statutes: the Emergency Medical Treatment and Active Labor Act (EMTALA), the Americans with Disabilities Act of 1990 (ADA), and the Rehabilitation Act of 1973 (Rehabilitation Act). All three statutes prohibit discrimination in one form or another against recipients of medical care. EMTALA is a federal anti-discrimination act requiring hospitals to screen and provide stabilizing treatment to individuals in "emergency medical conditions" before transferring them to other hospitals or releasing them. The recently enacted ADA

60. See supra notes 5-6 and accompanying text for a discussion of comfort care and futile medical treatment.
63. 42 U.S.C. §§ 12101-12213 (Supp. 1990) [hereinafter ADA].
65. 42 U.S.C. § 1395dd (Supp. 1993). EMTALA defines an “emergency medical condition” as “a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in (i) placing the health of the individual . . . in serious jeopardy, (ii) serious impairment to bodily functions, or (iii) serious dysfunction of any bodily organ or part.” Id. § 1395dd(e)(1)(A).
prohibits disability-based discrimination in places of public accommodation, including hospitals, and the Rehabilitation Act prohibits discrimination against an "otherwise qualified" disabled individual, solely by reason of his or her disability, for any program or activity receiving federal financial assistance. Each Act protects disabled individuals, including anencephalic infants, from being denied processes, benefits, and services offered to other recipients of medical care.

In *Baby K*, the United States District Court for the Eastern District of Virginia ruled that denying an anencephalic infant medical treatment violates the EMTALA, the ADA, and the Rehabilitation Act, and other state and federal statutes. The court held that because Baby K is considered a "handicapped" and "disabled" individual born with a congenital defect and entered the hospital in an "emergency medical condition" of respiratory failure, she could not be denied medical treatment. Although the standard treatment of anencephalic infants is only to provide the comfort care of nutrition, hydration, and warmth, the court ruled the hospital had a duty under EMTALA to use aggressive treatment to stabilize the emergency condition and treat Baby K in the same manner as any other individual suffering an emergency respiratory problem. By deferring to the legislative intent of these statutes, the court protected the anencephalic infant from discriminatory

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70. *Id.* at 1027. See also Bowen v. American Hosp. Ass'n, 476 U.S. 610, 624 (1986) (stating that the definition of "handicapped" under the Rehabilitation Act of 1973 to include an individual born with a congenital defect).
72. *Id.* at 1031.
73. See *supra* notes 5-6 and 60 and accompanying text; see also Johnson v. Thompson, 971 F.2d 1487, 1496 (10th Cir. 1992) (holding that physicians were not liable for breach of duty for administering only "comfort" or supportive care to an infant with spina bifida and anencephaly since the infant, like most anencephalic infants, would not have survived with the application of vigorous treatment, nor would her underlying defects have been cured).
74. *Baby K*, 832 F. Supp. at 1028. The statute recognizes that while hospitals and medical practitioners do not have a duty to provide aggressive means to treat anencephaly, they do have the duty to provide "stabilizing medical treatment" for any emergency medical condition. See 42 U.S.C. § 1395dd(e)(1)(A).
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This decision exhibited respect for Baby K's bodily integrity by requiring physicians to treat her for her emergency condition, rather than allowing her to die so that her organs might be used for transplantation to other children as some hoped.

2. The Court's Refusal to Allow Organ Procurement from Anencephalic "Baby Theresa"

In the somewhat similar widely publicized, landmark case of In re T.A.C.P., parents of an anencephalic infant called "Baby Theresa" requested that Florida courts declare her brain dead upon birth to allow her organs to be removed immediately for donation. Baby Theresa's parents had learned during pregnancy that Theresa would be born with anencephaly. They specifically decided to carry the fetus to term for the sole purpose of donating her organs to another child, and even arranged for a Cesarean section delivery to prevent any damage to the organs during the birth process. The family claimed that it was ethically appropriate to remove Baby Theresa's organs upon birth because anencephaly is "incompatible with life." The Florida Supreme Court, however, refused to declare the infant brain dead because under Florida law an individual may not be declared dead until there is irreversible cessation of circulatory and respiratory functions, or until all activity of the brain stem ceases. By the time Baby Theresa died naturally nine days after her birth, her organs had already begun to deteriorate and were not suitable for donation.

Baby Theresa's parents defended their request on constitutional and common law grounds. They argued that the constitutional right to privacy, the right to the free exercise of religion, the common law right to bodily integrity, the right to patient autonomy, and their rights as parental guardians enabled them to make medical decisions for their incompetent

77. Fla. Stat. ch. 382.009(1) (1991) (providing the UDDA requirements for death); In re T.A.C.P., 609 So.2d at 592 (contrasting the Florida statutes with the UDDA requirements for death).
child. The court disagreed with each of these rationales. The court upheld the medical standard that when a patient cannot choose non-treatment for herself, the presumption of life mandates treatment. The Florida court held that although parents have the privacy right to make decisions about nurturing and raising a minor child, the constitutional right to privacy does not extend to the extraction of organs that are necessary for support of the child's own life. The court stated it could not "authorize someone to take [a] baby's life, however short, however unsatisfactory, to save another child." Like Baby K, this decision provides that under the common law and statutory law, anencephalic infants are to be protected from organ procurement until the time of their natural deaths.

III. MEDICAL PROPOSALS AND UNCERTAINTIES

A. Four Proposals for Obtaining Organs from Anencephalic Infants

To be transplanted, an organ must be healthy and must be suitable for donation. The organ must function satisfactorily and be free from anomalies that would cause a chance of rejection by the organ recipient. Since the cause of anencephaly and other neural tube defects are believed to be multiple and undetermined, it is difficult for physicians to determine the suitability of the organs and preserve them for transplantation. Physicians, attorneys, and ethicists have cumulatively proposed four different methods for medically sustaining anencephalic infants in attempt to best prevent anencephalic organs from undergoing irreversible deterioration and hypoxic injury. The four proposals are as follows:

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79. The court clarified that the constitutional right to privacy applies to Baby Theresa regarding the decisions she would make about her own medical treatment, were she able, but it does not apply directly to decisions made by Baby Theresa's parents that are not in the best interests of the infant. In re T.A.C.P., 609 So.2d at 593 n.9.
80. Avila, supra note 76 (citing Trial Transcript, at 57-59, In re T.A.C.P., 609 So.2d 588 (Fla. 1992)).
82. See, e.g., Medearis & Holmes, supra note 12, at 391.
84. Committee on Bioethics, supra note 1, at 1116-17.
1. Resuscitating the infant at birth and maintaining its life with intensive care until total brain death or natural death occurs.  

2. Providing medical care to the infant until vital signs show impending cardio-respiratory death. At a point just before death, the infant is monitored and given maximum life support to preserve the organs until total brain death or natural brain death occurs.

3. Gradually "cooling" the anencephalic infant's body temperature to help preserve the organs. Although the infant's death is actually hastened by the cooling of its body, the claimed intention of the process is to preserve the infant's organs for transplantation and not to kill the infant.

4. Procuring organs from anencephalic infants before total brain death or natural death occurs. The rationale for this approach is that anencephalic infants are "brain-absent" and thus may be treated as though they were brain dead.

Because an anencephalic infant is expected to have only a short life span, it is argued that these methods of providing life support or cooling the infant's body temperature would not be too costly or too burdensome upon hospitals, physicians, staffs, or families. Certainly it would not be more costly than maintaining any other individual on life support. Yet, while each of these methods may seem appealing to attempt to preserve much needed organs for children awaiting transplants, they are rarely successful due to problems with the efficacy and suitabilit-

85. The study conducted at the Loma Linda Medical Center provided intensive care to six anencephalic infants from the date of birth until the infants met the legal criteria for total brain death. The average length of time necessary to maintain an infant until brain death is seven to fourteen days, however, only one of six infants became totally brain dead within the first seven days. Six babies were provided routine comfort care until signs of imminent death appeared, at which time the infants were given artificial respiration and intensive care to attempt to preserve their organs. Yet, no solid organs were procured for transplantation due to a lack of availability of specific recipients. Gianelli, supra note 42, at 2 (citing statements by Dr. Joyce Peabody, the head of the Loma Linda study); Peabody, supra note 2, at 345-46.

86. Justified by the "doctrine of double effect," a procedure which causes simultaneous positive and negative results is generally regarded as beneficial and not negative, so long as the positive effect is intended. Thus, preserving the organs is treated as the intended effect and the death of the infant is viewed as only an unfortunate associated effect. See Committee on Bioethics, supra note 1, at 1116.

87. This method is the most controversial approach and has been used in West Germany. Id. at 1117; see also Medearis & Holmes, supra note 12, at 392.
ity of the organs, and misdiagnosis of the anencephalic condition.

B. Problems with Efficacy and Suitability

For each of the first three methods described above, the infant first must be declared brain dead, or have died naturally, and the infant’s organs must be healthy and medically acceptable for transplant. These requirements are more challenging to satisfy than might be expected. First, it is sometimes difficult to obtain a declaration of brain death. A medical determination of brain death is not usually made until an infant is at least seven days old since a child is still developing during the first week of life.\(^8\) Second, no set criteria exist for determining brain death in children that are only newborn.\(^9\) Neurological criteria used in older children is not as effective for very young anencephalic infants because they are not as fully developed as other infants.\(^9\) Furthermore, the duration of the infant’s life is difficult to predict accurately, which is particularly stressful for parents who are making decisions about organ donation and attempting to arrange the logistics of an organ transplant.

Furthermore, many internal organs are medically unsuitable for organ donation. The organs of an anencephalic infant which suffer inadequate perfusion and a lack of oxygen contain anomalies rendering the organ unfit for donation.\(^9\) The 1987-88 Loma Linda Medical School study showed that anencephalic infants are not practical sources for organ transplantations because of these numerous organ anomalies.\(^9\) In the study, only one of the twelve attempts to procure usable organs from anencephalic infants was successful.\(^9\) In another study conducted at Brigham and Women’s Hospital between

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88. Committee on Bioethics, supra note 1, at 1117 (citing the Department of Health and Human Services Task Force on the Determination of Brain Death in Children, which recommends that the brain death criteria be limited to infants seven days or older).
89. Id.; see, e.g., Arras & Shinnar, supra note 9, at 2284; Report of the Task Force, supra note 8, at 298-300.
90. Committee on Bioethics, supra note 1, at 1117.
91. Committee on Bioethics, supra note 1, at 1116; see also Paliokas, supra note 4, at 197 (stating that owing to the absence of higher brain capacity, the infant “forgets” to breathe, causing deprivation of blood and oxygen to the organs).
92. Peabody et al., supra note 3, at 345-46, 350; see also supra note 85 and accompanying comments.
93. The study showed that when only routine care was provided, the organs deteriorated beyond use. When aggressive care was provided upon birth, the organs remained
1972 and 1988, there were major anomalies in the organs of seven of the thirty-nine anencephalic infants, which totaled 18% of the anencephalic infants.\textsuperscript{84} The quality of these vital organs were eroded even further by maintenance on life support machines.\textsuperscript{85}

Roughly 60% of anencephalic infants' organs will be too small to be transplanted due to premature birth or complications in the womb such as intrauterine growth retardation.\textsuperscript{86} Of the infants who are potentially suitable as organ donors, many will be aborted due to the increased technological abilities to detect neural tube defects during the early stages of pregnancy.\textsuperscript{87} Based on this information, there will be fewer suitable organs to procure from anencephalic infants as the years pass. Given the small number of anencephalic infants born each year, compared with the thousands of pediatric organs needed, the difficulty with organ compatibility, timing, and transportation make procuring organs from anencephalic infants unsuitable, inefficacious, and simply impractical.

C. Problems of Misdiagnosis

Error in diagnosis of anencephaly is of significant concern. Since anencephaly falls on a continuum with other serious congenital neural defects such as microencephaly and hydroencephaly, anencephaly is often difficult to accurately identify.\textsuperscript{88} To justify changing the UDDA definition of death or amending the UAGA to include anencephalic infants as organ donors it is absolutely necessary to maintain a high level of accuracy in the diagnosis of the condition. It is too risky to label an entire class of human being as legally dead without identifying their condition with medical certainty. Even the most able of physicians may disagree as to the diagnosis. The need for accuracy is predicated on the slippery slope doctrine, as it is

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\textsuperscript{84} Medearis & Holmes, supra note 12, at 391.
\textsuperscript{85} Truog & Fletcher, supra note 17, at 390.
\textsuperscript{86} Brandon, supra note 12, at 805.
\textsuperscript{87} Medearis & Holmes, supra note 12, at 392 (stating that "too many errors have been made for the diagnosis to be considered reliable as a legal definition of death"). \textit{See also} supra note 1 and accompanying text.
\textsuperscript{88} See Brandon, supra note 12, at 804 (stating that while anencephaly is obvious in some cases, there are still many instances where it is not as apparent).
essential to insure that other infants with less severe neural anomalies are not misdiagnosed as anencephalic, either innocently or intentionally, since their organs then also could be procured for transplant before their natural or brain deaths occur.

CONCLUSION

Indeed, it is true that changing the law to include anencephalic infants as organ donors before natural death or brain death may benefit some children anxiously awaiting organ transplants. Amending the law may also help our society redistribute precious and costly medical resources to those infants who have a greater chance of survival. Yet proposals to amend the UDDA or the UAGA are based on a motivation to satisfy a market economy and to meet the demand of organ shortages by increasing the supply of organs. These motivations may be noble to some, and even wise to others, but the means by which this goal is to be achieved are simply immoral. Anencephalic infants are not dead. Their organs should not be procured until they have died or have been diagnosed as brain dead. Until then, they are living, breathing human beings and should be treated with respect and dignity.

At the heart of this debate are questions about the principles of “life” and “death.” Some people define life by a heartbeat. Others define it as cognitive functioning. When it comes to decision making about newborn babies and parenting, personal and religious values play a large role. In a society where individuals are already skeptical about organ donation and drawing lines around the concepts of life and death, very few seem eager to think or speak in absolutes. More realistically, society is not comfortable with labeling as “dead” a group of infants who are already condemned to such a short and simple life. So until philosophers, bioethicists, lawmakers, and public citizens are able to find a middle ground or reach a consensus about these emotional issues, it is best to defend these newborn infants and protect their interests, and all human beings’ interests, in bodily integrity, personal dignity, and in life.