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The Anencephalic Baby Theresa: A Prognosticator of Future Bioethics

Julie Koenig*

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Abstract

In re T.A.C.P. is a case of first impression for any jurisdiction in the United States.

KEYWORDS: infants, rights, harvesting

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TABLE OF CONTENTS

I. INTRODUCTION	445
II. ANENCEPHALY DEFINED	448
III. CAUSATION AND PREVALENCE OF ANENCEPHALY ...	452
IV. DIFFERENTIAL DIAGNOSES OF ANENCEPHALY	459
V. WHOLE BRAIN DEATH AND THE ANENCEPHALY CHILD	461
VI. BEHAVIORS AND LIFE EXPECTANCY OF ANENCEPHALIC INFANTS	467
VII. DONATION VS. PROCUREMENT: THE PARENT'S RIGHTS VS. THE CHILD'S RIGHTS	470
VIII. PERSON VS. NON-PERSON: INFANTICIDE VS. HARVESTING	475
IX. THE BIOETHICAL POSITION OF CHILDREN	481
X. PROTECTIONS UNDER THE LAW	484
XI. BIOETHICAL CONCERNS IN ORGAN TRANSPLANTATION	491
XII. CONCLUSION	496

I. INTRODUCTION

*In re T.A.C.P.*¹ is a case of first impression for any jurisdiction in the

* Julie Koenig is a practicing family law attorney in Fort Lauderdale, Florida. B.A. Northwestern University; M.A., Michigan State University; J.D., Nova University Shepard Broad Law Center. The author would like to extend her thanks and appreciation to her (former) law clerk, Catherine L. Roselli, for all of her assistance in the writing of this article. The author would also like to extend her gratitude to Maggie Lacayo and Debbie Stern for their medical research.

1. No. 92-8255(18) (Fla. 17th Cir. Ct. filed Mar. 27, 1992), No. 92-0942 (Fla. 4th Dist. Ct. App. filed March 27, 1992), No. 79, 582 (Fla. filed Apr. 1, 1992). Theresa Anne Campo Pearson was an anencephalic infant born in Fort Lauderdale, Florida on March 21, 1992. Her birth touched off a lengthy court battle between her biological parents and the hospital where she was born over whether her organs could be harvested for possible use by other handicapped children before she met the requirements of cardiopulmonary or whole brain death. The author was court-appointed as the child's Guardian Ad Litem by the Honorable Estella Moriarty of the Seventeenth Judicial Circuit, in and for Broward County, Florida, and

United States. Never before have parents of an anencephalic child filed suit seeking judicial permission to remove their child's organs while the child had autonomous cardiopulmonary function and brain stem activity. The suit was aimed at harvesting Baby Theresa's organs, and concomitantly, ending her life. However, this case has ramifications beyond the removal of organs from one live born anencephalic child prior to a legal determination of death; this case introduces the proposition that certain human beings, born alive, may not be legal "persons" because they lack cognitive capacity, are soon to die, or because their organs are useful to others who are deemed legal "persons." To declare one category of severely disabled live-born humans as "non-persons" because of their handicaps could disqualify from personhood other categories of disabled human beings. Furthermore,

[m]anipulating the definition of death-by including anencephalic infants whose spontaneous breathing, sucking, crying, and the like separate them from the dead bodies that society is usually willing to label cadavers and bury-may undermine the public's already tenuous confidence in brain-based determinations of death . . . [and] also cause problems for the parents of such infants who wish to sustain them with nutrition and comfort during the dying process.²

Ultimately, if Baby Theresa is a "non-person," she may not be subject to the protections of the state and federal constitutions; if she is a "person," taking her life by removing her organs may be considered infanticide.

Historically, handicapped children have been treated differently from normal children. However, even normal children have had to live at the mercy or the pleasure of those family members who have control over them. As the parent of a retarded child, author Pearl S. Buck reproved the parents of other severely handicapped children who chose death rather than life for their children:

And yet I know that the parents of whom I read do wrong when they take to themselves a right which is not theirs and end the physical lives of their children. In love they may do it, and yet it is wrong. . . . Were the right to kill any innocent person assumed by society, the effect would be monstrous. For first it might be only the helpless children who were killed, but then it might seem right to kill the helpless old; and then the conscience would become so dulled that

she participated in the case throughout its journey to the Florida Supreme Court.
2. D. Alan Shewmon, MD, et al., *The Use of Anencephalic Infants as Organ Sources*, 261 JAMA 1773, 1778 (1989).

prejudice would give the right to kill, and persons of a certain color or creed might be destroyed. The only safety is to reject completely the possibility of death as a means of ending an innocent life, however useless. The damage is not to the one who is killed, but to the one who kills.³

Baby Theresa's life began on Saturday, March 21, 1992, at Broward General Medical Center in Fort Lauderdale, Florida. Her parents, Justin Demire Pearson and Laura Ann Campo, had five other children between them. At home, Baby Theresa had two full-blood siblings—a brother and a sister; living outside the home, Baby Theresa had a maternal half-brother and two paternal half-siblings. Laura Campo, Baby Theresa's mother, did not learn that her unborn child suffered from anencephaly until she was in her eighth month of pregnancy. Prior to Baby Theresa's birth, her family had been involved with several state and local governmental agencies.

Baby Theresa appeared to be a normal baby wearing a cap over her upper head. She breathed on her own. Her heart beat without mechanical assistance. She moved her arms and legs. And, she resembled a normal newborn in her behavior. Essentially, Baby Theresa appeared, to all who saw her, to be alive.⁴ Except that beneath Baby Theresa's cap, only a brain stem was present.

This article will describe the similarity of a live-born anencephalic infant's behavior to that of a normal newborn. It will investigate the child's life span, development (prenatal and postnatal), and the utility, causation and incidence of the anencephalic condition, as well as the difficulties inherent in the precise diagnosis of anencephaly. More importantly, it will address a series of complicated and perplexing questions. For example, is it legally possible to take an autonomously breathing baby, whose blood is independently circulating, into an operating room, remove her heart, liver and kidneys, and then declare her dead? Is it possible to terminate the life of a human being without violating the law?

Because "persons" have a right to life under the federal and state constitutions, taking the life of Baby Theresa would be a violation of her rights, if she were considered a "person." However, if Baby Theresa and anencephalic infants were determined to be "non-persons," then she would no longer have the right to life and equal protection under the federal and

3. PEARL S. BUCK, *THE CHILD WHO NEVER GREW* 28 (1950).

4. Baby Theresa endured a gradual deterioration of her solid organs due to the diminished flow of blood and lymphatic fluid to those organs. This process is similar to the dying process for all human beings.

state constitutions. Declaring a category of handicapped human beings to be "non-persons" may have a larger impact on other categories of handicapped persons because of the very limited utility of anencephalic infants as organ sources.

The solution to the complicated and perplexing puzzle of Baby Theresa's personhood anticipates bioethics in the 21st Century. For instance, will the weakest, most handicapped, most powerless members of our society be denied personhood and be sacrificed for the stronger, less handicapped and more powerful? Will personhood and human rights be granted selectively to human beings depending on the size of their brains, the duration of their lives, or whether certain nerves or muscles work?

II. ANENCEPHALY DEFINED

"Anencephaly is generally described as the congenital absence of skull, scalp and forebrain (cerebral hemispheres)."⁵ However, an anencephalic infant is born *with* a brain. Anencephaly is a congenital malformation of the brain in which the volume of nervous tissue can vary "from only a few grams up to a normal full-term brain weight."⁶ Heart and lung function, as well as body temperature, are controlled by the brain stem which may show "a spectrum of involvement . . . from relatively normal to totally absent."⁷ Developmentally,

[a]nencephaly is an extremely early malformation as the neural tube begins to form in the human in day 16 of gestation. It is thought that closure of the neural tube first occurs on day 22 in the region of the future brain stem. Fusion then proceeds in a headwise direction between day 23 and 26. . . . Anencephaly has been described as a sheet of cerebral tissue rather than the cerebral cortices, lying open over an intact hind brain. In an older fetus, anencephaly presents as an open cranial vault with variable absence of the cerebrum and cerebellum but with preservation of the hind brain. The eyes are usually present. The surface of the nervous system is covered with a vascularized spongy surface suggesting there has been degeneration of the exposed tissue. There is variability in both the types of skull malformation and in the extent of cerebral damage. It is suggested that the majority of cases of

5. D. Alan Shewmon, *Anencephaly: Selected Medical Aspects*, 18 HASTINGS CTR. REP. Oct.-Nov. 1988, at 11.

6. *Id.* (footnote omitted).

anencephaly are [sic] related to a failure of closure of the neural tube. This indicates that the disorder must be present before 24 days in anencephaly.⁸

Although live born anencephalic infants lack a functional cerebral cortex, they usually have a brain stem that sustains and regulates a wide variety of vital bodily functions, including spontaneous respiration.⁹ Thus, it would be more accurate to describe anencephalic infants as higher brain absent than as brain absent. According to the current definition of brain death (i.e. the complete and irreversible cessation of all brain functions, including those of the brain stem), utilized in all jurisdictions in the United States, anencephalic infants are indisputably alive. Indeed, no person with spontaneous, unassisted respiration meets either the current common law criteria for death (the cessation of cardiopulmonary function), or the statutory definition for whole brain death as outlined in all state statutes.¹⁰

Redefining "death" would allow the organs from an anencephalic infant to be harvested while the baby breathes without mechanical assistance, while her blood circulates and while she moves and reacts. The current concept of whole brain death is a "refinement and updating of measurements for determining whether persons are dead, or when they are dead, in the presence of life supports or other interventions that obscure ordinary means of determining death."¹¹ Furthermore, calling an anencephalic infant "dead" while the child has autonomous cardiopulmonary function, and while she moves and reacts is contradicted by a visual inspection of the child. Redefining death for one category of severely handicapped live born human beings would inevitably lead to a constitutional challenge and could, if the

8. B.C. McGillivray, *Anencephaly-The Potential for Survival*, 20 TRANSPLANTATION PROC. 9, 9 (5th Supp. 1988) (footnotes omitted).

9. In normal neonates who are born with a cerebral cortex, the upper brain is "much less microscopically developed than the brain stem, and the cerebral cortex is relatively non-functional." See Shewmon, *supra* note 2, at 1776.

10. John D. Arras & Shlomo Shinnar, *Anencephalic Newborns as Organ Donors: A Critique*, 259 JAMA 2284, 2285 (April 15, 1988); see also PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAV. RES., *DEFINING DEATH* (1981); *Guidelines for the Determination of Brain Death in Children: Report of the Task Force*, 80 PEDIATRICS 298-300 (1987); *Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death: A Definition of Irreversible Coma*, 205 JAMA 105-33 (1980).

11. Larry R. Churchill & Rosa Pinkus, *The Use of Anencephalic Organs: Historical and Ethical Dimensions* 68 MILBANK Q. 147, 158-59 (1990).

re-definition survives legal challenge, provide a "wedge" for the expansion of that handicapped category to include other handicapped human beings.

Another method by which the organs of an anencephalic infant may be harvested while the child has autonomous cardiopulmonary function, while she moves and reacts, is to exclude the anencephalic infant from the category of "personhood." If the child is no longer a person, "then the moral opprobrium and legal restraints from harming, wronging, killing or using [the child] for other purposes are diminished."¹² To date, no jurisdiction in the United States permits the use of anencephalic infants' organs without meeting the legal criteria of death established for all other persons.¹³ California, New Jersey and Florida considered legislative revisions that would have permitted the harvesting of organs from anencephalic infants who still had cardiopulmonary and brain stem functions; however, all three legislatures refused to pass the legislation.¹⁴

The non-person status based on the lack of certain minimal cognitive capacities may later be enlarged by scientists or lawmakers, not only to include severely brain damaged infants or profoundly demented adults, but also to include all normal newborns who, some scientists allege, fail to qualify under the cognitive capacity rule.¹⁵ Cognitive capacities usually include: "(1) the ability to be conscious of oneself as existing over time; (2) the ability to appreciate reasons for or against acting; and (3) the ability to engage in purposeful action."¹⁶

A third strategy for using anencephalic infants' organs while the child has autonomous cardiopulmonary function, and while she moves and reacts, is "temporizing" or keeping the dying infant's organs fresh and fending off "deterioration during the dying process."¹⁷ This is accomplished by intubation and ventilation of "the infants for a period . . . while regularly

12. *Id.* at 160.

13. *Id.* at 161.

14. See Kathleen L. Paliokas, *Anencephalic Newborns as Organ Donors: An Assessment of "Death" and Legislative Policy*, 31 WM. & MARY L. REV. 197, 206 (1989); Jay A. Friedman, *Taking the Camel by the Nose: The Anencephalic as a Source for Pediatric Organ Transplants*, 90 COLUM. L. REV. 917, 937 (1990). The Florida House of Representatives considered an anencephalic exception in 1988; however, the proposed bill never made it out of the Health and Rehabilitative Services Subcommittee. See Fla. H.R. 1089, Reg. Sess. (1988).

15. ALLEN E. BUCHANAN & DAN W. BROCH, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 260 (1989).

16. *Id.*

17. Churchill & Pinkus, *supra* note 11, at 164.

checking for brain death."¹⁸ Ordinary medical care requires that patients are not overtreated when treatment is futile. Non-treatment of patients whose conditions are such that any treatment is useless is considered an appropriate form of good patient care. The proposed temporizing strategy would be overtreatment of the anencephalic infants because anencephalic infants are dying; prolonging their death is not in the children's best interests. Consequently, any prolongation of an anencephalic child's death is, instead, to benefit a potential recipient of the anencephalic child's solid organs.

Most anencephalic infants are stillborn or die within a few days of birth. However, some anencephalic infants have survived for weeks, months, and very few for years.¹⁹ The causes of death in live born anencephalic infants include aspiration, infection (usually through the lesion in the head), adrenal gland insufficiency and poor regulation of body temperature.²⁰ The terminal event is usually cardiorespiratory arrest and the inadequate passage of fluid through the blood vessels and lymphatic system, "rendering the heart, liver, and kidneys unsuitable for transplant."²¹ Corneas and skin might be salvaged, but there is little demand for these from neonates.²²

Strategies for permitting the use of anencephalic infants' organs before the infant's somatic death have grave importance from the point of view of the dying infant, and far more long range effect

with the larger impact on society of establishing a tolerance toward sloppiness in either the conceptualization or implementation of standards for determining death, particularly when this is motivated both by pressure to obtain organs and by an implicit depreciation of a being whose humanity is at least possible, if not probable.²³

The debate over the use of anencephalic infants as organ donors is both the latest chapter in the lengthy saga of how to treat patients claimed not to have achieved, or incapable of achieving, "personhood," and an opening for those who believe it is time to amend the definition of death to include

18. *Id.*

19. Norman Fost, *Organs from Anencephalic Infants: An Idea Whose Time Has Not Yet Come*, 18 HASTINGS CTR. REP. Oct.-Nov. 1988, at 5, 6; see generally McGillivray, *supra* note 8.

20. Fost, *supra* note 19, at 6.

21. *Id.*

22. *Id.*

23. Shewmon, *supra* note 2, at 1779.

"higher" brain or "neocortical" criteria for death. This amendment would enable humans without cerebral cortex function, but with brain stem function, to be declared legally dead.

In spite of assurances to the contrary, it is highly unlikely that the logic undergirding these exceptions to the whole brain or cardiopulmonary criteria for death can be confined to anencephalic babies. The question of removing vital organs from anencephalic infants is inextricably bound up with other biomedical issues, including last trimester abortion, harvesting fetal body parts, treatment of newborns, both normal and defective, and treatment of gravely disabled adults. "In large measure, the impetus for redefinition does not spring from any merit intrinsic to the question, nor from our concern for the group in question, but rather because we have some use in mind for them. Otherwise, the issue of 'personhood' would be of only academic interest."²⁴

While anencephalic infants, as well as all human beings, are in the process of dying, their solid organs are gradually deteriorating because of insufficient passage of blood and lymphatic fluids to those organs. Consequently, the irreversible injury to the solid organs during the dying process causes the organs to be unsuitable for donation by the time that death is achieved.²⁵

III. CAUSATION AND PREVALENCE OF ANENCEPHALY

The specific cause of anencephaly is usually not identifiable. A multitude of factors have been recognized, including chromosomal abnormalities, "disruption of normal processes of development includ[ing] amniotic bands and fetal adhesions to the placenta . . . at or before the induction of cerebral development."²⁶ Furthermore, maternal factors such as hypothermia, folate deficiency, zinc deficiency and copper deficiency are associated with anencephaly. Finally, the incidence of anencephaly increases in twin births.²⁷ Other maternal factors emerge as risks in some studies but not in others: these factors include age, previous births of

24. Churchill & Pinkus, *supra* note 11, at 162.

25. Generally, the dying process is similar for all humans experiencing somatic death; solid organs deteriorate during the dying process, making them unsuitable after somatic death. Candidates for organ donation experience brain death while their organs are supported by mechanical assistance. See Medical Taskforce on Anencephaly, *The Infant with Anencephaly*, 322 NEW ENG. J. MED. 669, 670 (1990).

26. *Id.*

27. *Id.*

offspring, birth month and ethnic origin.²⁸ Environmental factors may also play a part in the cause of anencephaly. Additional environmental factors cited in some studies include drug use, socioeconomic status, infections, diet and composition of drinking water.²⁹

"[I]f the laws were revised to permit harvesting from live anencephalics, the number of children who die each year from congenital kidney, heart and liver disease would still be insignificantly reduced."³⁰ Dr. D. Alan Shewmon, Associate Professor of Pediatric Neurology at the University of California School of Medicine, has written extensively on anencephaly, postulating that eleven successful transplants per year would be the beneficial result of harvesting the organs of all live born anencephalic infants before they meet the criteria of whole brain or cardiopulmonary death.³¹

The incidence of anencephalic births has been declining worldwide over the past two decades.³² The increased use of prenatal alpha-fetoprotein screening and ultrasound may further decrease the incidence of anencephalic births.³³ Effective alpha-fetoprotein screening in combination with ultrasound has been eighty percent to one hundred percent sensitive in diagnosing anencephaly after the sixteenth week of gestation.³⁴ Thus, many parents, after prenatal screening, have voluntarily terminated their pregnancies by abortion in the second trimester.³⁵ In California, approximately fifty percent of all pregnancies are screened in the second trimester; ninety-five percent of detected anencephalics are aborted.³⁶

Moreover, many obstetricians consider it improper to encourage a woman to carry a second trimester anencephalic fetus to term, given the increased risk of complications to the pregnancy.³⁷ For these reasons, the possibility of organ donation would be expected to have much more of an impact on parental decisions to terminate pregnancy following a diagnosis of anencephaly in the third trimester than in the second. Theoretically, a

28. *Id.* at 671.

29. *Id.*

30. Shewmon, *supra* note 2, at 1780.

31. *Id.* at 1775. Theoretically, the eleven transplants would comprise of nine heart transplants, two liver transplants and zero kidney transplants. *Id.*

32. Shewmon, *supra* note 5, at 12.

33. *Id.*

34. Jeffrey R. Botkin, *Anencephalic Infants As Organ Donors*, 82 *PEDIATRICS* 250, 251 (1988).

35. *Id.*

36. Friedman, *supra* note 14, at 923 n.31.

37. Shewmon, *supra* note 2, at 1774-75.

projected 1,125 anencephalic births would occur in the United States each year without increased alpha-fetoprotein and sonogram screenings.³⁸ Of the projected 1,125 anencephalic children, approximately 911 would be unaffected by prenatal screenings, since prenatal alpha-fetoprotein screenings reach fewer than one-third of the current pregnancies.³⁹ From fifty percent to ninety percent of unscreened anencephalic children are stillborn, with a middle figure of two-thirds making the estimated annual number of live anencephalic births in the country 304.⁴⁰ The anencephalic infant is generally stillborn because of the child's inability to withstand pressures on her exposed brain as she travels through the birth canal.⁴¹ Lowering the stillborn rate by elective cesarian section is a maternal risk that most medical professionals agree would be unwarranted in this type of situation.⁴²

"Slightly more than half of anencephalic births are premature and some 50% to 80% have birth rates less than 2 kilograms."⁴³ Approximately sixty percent of anencephalic infants who survive the birth process will be too small to provide useful organs for transplantation, reducing the above estimated 304 live born anencephalic to 122 potentially useful ones.⁴⁴ If two-thirds of the parents are willing to donate, the annual number of useful anencephalics decreases to eighty-one.⁴⁵ "One third to one half of anencephalic infants have associated gross malformations of at least one other organ system."⁴⁶ "[T]he overall experience with long-term graft survival from infant kidney donors in general has been poor Typically, the kidneys from infant liver or heart-donors go unclaimed."⁴⁷ "Cardiovas-

38. *Id.* at 1174. Dr. Shewmon estimates 1,125 anencephalic births per year. Some studies estimate the number of anencephalic babies born each year from 1,000 to 1,800; the Center for Disease Control estimates from 2,000 to 3,000; see also Friedman, *supra* note 14, at 921 n.18.

39. Shewmon, *supra* note 2, at 1774-75.

40. *Id.* at 1774.

41. Shewmon, *supra* note 5, at 13.

42. *Id.*

43. Shewmon, *supra* note 2, at 1774.

44. *Id.*; see also Giroud, *Anencephaly*, 30 HANDBOOK OF CLINICAL NEUROLOGY, 173, 176 (1977).

45. Shewmon, *supra* note 2, at 1774-75.

46. *Id.*; see also Milnick & Myrianthopoulos, *Pathological Findings in a Prospectively Collected Series of Anencephalics: Studies in Neural Tube Defects II*, 26 AM. J. OF MED. GENETICS, 797 (Apr. 1987).

47. Shewmon, *supra* note 2, at 1774-75; see also Effenger & Fine, *Renal Transplantation*, PEDIATRIC NEPHROLOGY, 828 (1987); Lim, Wassner & Martin, *Current Thinking in Transplantation in Infants & Children*, 32 PEDIATRIC CLINICS OF N. AM. 1203 (1985).

cular malformations occur in some 8 to 41 percent of anencephalics."⁴⁸ Around one-fourth of anencephalic infants have gross gastrointestinal anomalies, including compromised livers.⁴⁹

Not every potentially transplantable organ finds its way into a recipient. Approximately "25% of all organ referrals (all ages combined) are found acceptable by established organ networks."⁵⁰ Even using estimates of fifty percent and twenty percent long-term survival for recipients of newborn hearts and livers respectively, the yearly number of patients in the country actually benefiting "from anencephalic kidney, hearts and livers optimistically projects to zero, nine and two respectively."⁵¹ Dr. Shewmon estimates that by 1998, with projected scientific advances in transplantation, twenty-five, twelve, and seven infants each year, at the very most, will benefit from kidney, heart and liver transplants respectively, if the laws were changed to allow organ transplantation from anencephalic infants who have not met the whole brain death criteria.⁵² Of course, increased alpha-fetoprotein screening with concomitant abortion elected in the second trimester, could again lower the estimated number of successful organ transplants by lowering the number of anencephalic births.

Estimates of approximately forty-one anencephalic infant organ transplants, with nine reports of transplant success over the past two decades, have been subject to scrutiny. The medical community believes that some physicians may be "ignoring the mandates of current law" and are illegally using the organs of anencephalic infants.⁵³ In fact, as detailed in a New England Journal of Medicine article in April 1987, three transplants occurred in Germany without a diagnosis of whole brain death in the two anencephalic infant sources.⁵⁴ The infants were born, intubated, and the organs removed, without further diagnosis.⁵⁵ All three of the transplanted organs harvested from the anencephalic infants were rejected within six

48. Shewmon, *supra* note 2.

49. *Id.*

50. *Id.* at 1774.

51. *Id.* at 1775.

52. *Id.*

53. Thomas Leggans, *Anencephalic Infants as Organ Donors: Legal and Ethical Perspectives*, 9 J. LEGAL MED. 449 (1988); see also Anderson, *Surgeons Want the Organs of Babies 'Born Brainless'*, 112 NEW SCIENTIST 20 (1986); Medical Task Force on Anencephaly, *supra* note 25.

54. Wolfgang Holzgreve et al., *Medical Intelligence: Kidney Transplantation from Anencephalic Donors*, 316 NEW ENG. J. MED. 1069 (April 1987).

55. *Id.*

months of the publication of the article.⁵⁶ Harvesting anencephalic infants' organs is no longer performed in Germany as a result of the public protest stemming from these transplants.⁵⁷ Furthermore, in Britain, a physician was under criminal investigation for having allegedly removed organs from an anencephalic infant before the neonate was legally dead,⁵⁸ and in 1973, an unsuccessful kidney harvesting was performed by a Dr. Lawson on a live born anencephalic child delivered by cesarian section.⁵⁹

In October 1987, Dr. Leonard Bailey⁶⁰ of Loma Linda University Medical Center in Los Angeles, California, transplanted the heart of an anencephalic infant, named Baby Gabrielle, into newborn Baby Paul.⁶¹ This transplant formed the platform for a protocol developed by Loma Linda as the basis for working with anencephalic infants as organ sources. In 1987 through 1988, twelve live born anencephalic babies were selected for the protocol and were placed on respirators in order to assist the infants with ventilation.⁶² The children were given intensive care to preserve their organs.⁶³

Ten out of the twelve live-born anencephalic infants entered into Loma Linda's protocol did not meet that institution's criteria for brain death within the specified 7-day limit, at which point the infants were disconnected from the ventilators and allowed to die. Even modifying the protocol, so that resuscitation and ventilating assistance not be provided until the infant was near death did not improve the yield over the original procedure of intubation and ventilation immediately after

56. Telephone interview with Dr. Wolfgang Holzgreve, Staff Doctor at Wilhelms University in Munster, Germany (Aug. 11, 1992). Dr. Holzgreve reported that the current German law prohibits the removal of organs from anencephalic infants prior to whole brain death, and that the earlier program where the harvesting of anencephalic organs took place, resulted in public outcry and a reduction in the public confidence in organ transplantation and organ donation.

57. *Id.*

58. Vines, *Row Over Anencephalic Babies Reaches Britain*, 115 NEW SCIENTIST 17 (1987); see also Shewmon, *supra* note 2; R. K. Lawson et al., *Hyperacute Renal Allograft Rejection in the Human Neonate*, 10 INVEST. UROL. 444-49 (1973).

59. Shewmon, *supra* note 2, at n.17.

60. Beth Brandon, *Anencephalic Infants as Organ Donors: A Question of Life or Death*, 40 CASE W. RES. L. REV. 781, 781-82 (1989-90). Previously, in 1984, Dr. Bailey had transplanted a baboon heart into "Baby Fae," a twelve day old baby girl who survived twenty days.

61. *Id.*

62. Shewmon, *supra* note 2, at 1778.

63. *Id.*

birth. One of these babies survived at home for two months following discharge.⁶⁴

It was postulated that intubation and ventilation enhanced the viability of the brain stem and prolonged brain death in the anencephalic infants.⁶⁵

Out of the twelve anencephalic infants in the Loma Linda protocol, whole brain death was confirmed in only two infants while they were ventilated mechanically. Even though they could legally be organ donors, no organs were taken from these children and no transplants were done.⁶⁶ The two infants did not become organ donors because recipients were not available.⁶⁷ Dr. Joyce Peabody, Chief of Neurology at Loma Linda during the time period that the protocol was being utilized, acknowledged that her program was a failure in an interview to the *Los Angeles Times*. Dr. Peabody stated: "Certainly, if the only outcome you are looking at is the number of solid organs transplanted, our program has failed and failed dismally."⁶⁸ Overall in the Loma Linda program, respiratory support appeared to promote the infants' long-term survival, prolong their dying processes, and possibly expose them to pain.⁶⁹ Furthermore, the protocol seemed to be of questionable efficacy in saving the integrity of the children's remaining organs.⁷⁰ "Loma Linda . . . suspended its program in part because it wanted to avoid accusations of organ farming."⁷¹

Four years after the Loma Linda protocol ended, Dr. Peabody, gave another interview to Diane Gianelli of the *American Medical News*.⁷² When asked why the protocol was terminated, Dr. Peabody responded:

We were already setting a new precedent in terms of initiating intensive care on one human being for the benefit of another. And to do that

64. *Id.*; see also James W. Walters & Stephen Ashwal, *Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues*, 18 HASTINGS CTR. REP. Oct.-Nov. 1988, at 19.

65. *Id.*

66. Joyce L. Peabody, et al., *Experience with Anencephalic Infants as Prospective Organ Donors*, 321 NEW ENG. J. MED. 344, 350 (1989).

67. Brandon, *supra* note 60, at 805; see also Goldsmith, *Anencephalic Organ Donor Program Suspended: Loma Linda Report Expected to Detail Findings*, 260 JAMA 1671 (1988).

68. Brandon, *supra* note 60, at n.178.

69. *Id.*

70. *Id.*

71. *Id.* at 806.

72. Diane Gianelli, *Calling Anencephalic Donors Dead: Transplant Study Director Asks: Would You Bury a Breathing Baby?*, AM. MED. NEWS, June 29, 1992, at 2.

with a clear additional risk of prolonging the baby's dying did not seem ethically acceptable to me. So, with no benefit from the program and with this potential additional risk, we stopped, and have no plans to continue along those same lines.⁷³

When asked what she thought of the Florida proposal to redefine death in order that anencephalic infants may be declared legally dead at birth, Dr. Peabody responded:

If you're going to call these infants dead, you're going to have to call them dead-period. So the anencephalic infant would be born-and what would you do? Would you write a birth certificate and then immediately write a death certificate? Would you never write a birth certificate? Would there be no legal distinction between a stillborn anencephalic infant and an anencephalic infant who was breathing? Would there be no distinction between an anencephalic infant whose parents wanted to donate and an anencephalic infant whose parents didn't want to donate? . . . Two anencephalic infants lying side by side with exactly the same vital signs and exactly the same appearance: Would you call one alive and one dead? I think legally, with all the rules of discrimination, you'd have to call them both the same. And, as dramatic as it sounds, if you were to declare anencephalic infants dead for purposes of organ donation, it would mean that you would be removing hearts from babies that breathe, suck, and cry. I would need to have the individuals who passed that law feel that if it were not for organ donation, they would be equally comfortable in burying a baby who was breathing, sucking, kicking and crying.⁷⁴

Although anencephaly may currently result in an excess of 300 live born anencephalic children each year, many of the children's organs are severely compromised by other anomalies and from low birth weights. Long-term graft survival indicates that approximately eleven children each year *might* benefit from utilization of all of the anencephalic children who fail to meet the standards of whole brain or cardiopulmonary death. "Might" is the operative word, and with the increased use of alpha-fetoprotein screening and the expansion of prenatal care, the incidence of live born anencephalic infants may diminish even further.

73. *Id.*

74. *Id.*

IV. DIFFERENTIAL DIAGNOSES OF ANENCEPHALY

Advocates of harvesting anencephalic infants' organs before the neonates satisfy the criteria of cardiopulmonary or whole brain death argue that anencephaly is an easily diagnosed, clearly defined condition, and that it does not lend itself to misdiagnosis. Therefore, they argue that creating an exception to whole brain or cardiopulmonary death for anencephalic children would have only a limited application. However, the medical literature is quite clear that, in fact, anencephaly is not always easily diagnosed and clearly defined.

The uncertainty of diagnosis is an additional problem. . . . Anencephaly, like all malformations, lies on a continuum with other developmental defects of the central nervous system. While infants at the extreme end of the spectrum clearly have no cerebral tissue, others will have some rudimentary cerebral tissue. And even if there could be agreement on the criteria necessary and sufficient to define anencephaly, there would be problems of misdiagnosis.⁷⁵

According to the Ethics Committee for the United Network for Organ Sharing's Report "The Anencephalic Infant as an Organ Source: Medical and Ethical Considerations,"⁷⁶ conditions which may be confused with anencephaly include the following:

Hydranencephaly: internal absence of cerebral hemispheres with hydrocephalus.

Iniencephaly: an open fissure including brain tissue and the spinal column, a growth disorganized embryo, multiple malformations.

Microcephaly with encephalocele: abnormally small head, brain tissue protrudes through a fissure.

Amniotic band disruption: fibrous bands that develop and entangle fetal parts in utero; may entangle the cranium and inhibit or prevent further development of the brain and spinal column.⁷⁷

Furthermore, in their textbook on anencephaly, Lemire and his colleagues stated, "[a]n almost incomprehensible array of synonyms and classifications of anencephaly exists in the literature; many include entities now considered

75. Fost, *supra* note 19, at 8.

76. UNITED NETWORK FOR ORGAN SHARING, THE ANENCEPHALIC INFANT AS AN ORGAN SOURCE: MEDICAL AND ETHICAL CONSIDERATIONS (1989).

77. *Id.* (emphasis added).

to be pathogenetically unrelated to the anencephaly spectrum.⁷⁸ Exencephaly, exposure of the brain, and pseudencephaly, massive "area cerebrovasculosa" imitating the shape of the brain that it replaces, are other congenital conditions which overlap with anencephaly.⁷⁹ Encephalocele, defined as "hernias of the brain protruding through a congenital opening of the skull," is closely related to exencephaly and anencephaly.⁸⁰ If the protruding brain of an exencephalic infant deteriorates, anencephaly results.⁸¹ If it is covered by skin or epithelium, and persists, encephaloceles are formed.⁸² The distinction may be obscure because of the similarity of the two conditions. Although most cases of anencephaly may be diagnosed without risk of error, "[n]evertheless, the commonly encountered contention that 'anencephaly' is so well defined and so distinct from all other congenital brain malformations that misdiagnosis cannot occur and that organ-harvesting policies limited to 'anencephalics' cannot possibly extend to other conditions, is simply false."⁸³

"Errors in diagnosis have been described in the literature, by surveillance programs, and by [the Medical] [T]ask [F]orce [on Anencephaly] in a survey of pediatric training programs."⁸⁴

There is no anomaly that cannot be misdiagnosed, and this holds particularly true for anencephalic infants. For example, one baby entered into [Loma Linda University Medical Center's] protocol was later referred back to an out-of-state medical center when [Loma Linda University Medical Center] doctors determined the baby was not a true anencephalic.⁸⁵

In fact, learning from the experiences of the Loma Linda protocol, it has been reported that several "good" physicians referred infants to the protocol that suffered from "less severe anomalies" than anencephaly for organ

78. Shewmon, *supra* note 5, at 11 (quoting RONALD LEMIRE, ET. AL., ANENCEPHALY 5 (1978)).

79. D. Alan Shewmon, *Anencephaly: Selected Medical Aspects*, 18 HASTINGS CENTER REP. 11, 11-12 (1988).

80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.* at 12.

84. Medical Task Force on Anencephaly, *supra* note 25, at 670.

85. J. C. Wilke & Dave Andrusko, *Personhood Redux*, 18 HASTINGS CENTER REP., Oct.-Nov. 1988, at 30, 32 (referring to a telephone interview with Richard Schaefer, Director, Loma Linda University Medical Center (July 6, 1988)).

donation.⁸⁶ For example, some of the infants referred suffered from "an abnormal amount of fluid around the brains or those born without kidneys but with a normal brain."⁸⁷ Moreover, the referring physicians could not "understand the difference" between such newborns and anencephalics.⁸⁸ These "bad" referrals prompted Dr. Joyce Peabody, the Director of the protocol, to admit: "I have become educated by the experience. . . . The slippery slope is real."⁸⁹ Furthermore, the fact that several doctors can disagree on a diagnosis of anencephaly indicates "that the enthusiasm for using anencephalic [infants as organ sources] does indeed quickly extend to other categories of dying infants."⁹⁰ "[P]ermitting the active termination of anencephalic infants may be the gradual exploitation of the vulnerable and the progressive brutalization of medicine and society."⁹¹ Thus, anencephaly lies on a continuum with other cerebral disabilities and can be misdiagnosed.

V. WHOLE BRAIN DEATH AND THE ANENCEPHALIC CHILD

The Uniform Determination of Death Act⁹² and the Uniform Anatomical Gift Act⁹³ were written in order to clarify the definition of "death" and to facilitate organ transplantation in the United States.⁹⁴ The common law cardiopulmonary determination of death required expansion after the introduction of mechanical respirators which produced cardiopulmonary function in persons who would be dead without mechanical assistance. "The Uniform Determination of Death Act defines death as 1) the irreversible cessation of circulatory and respiratory function or 2) the irreversible cessation of all functions of the entire brain, including the brain stem."⁹⁵ Florida Statute section 382.009 provides that brain death occurs upon the "irreversible cessation of the functioning of the entire brain, including the

86. Shewmon, *supra* note 2, at 1775.

87. *Id.*

88. *Id.*

89. Robert Steinbrook, *Frank Admissions End Infant Organ Harvesting*, L.A. TIMES, Aug. 19, 1988, at 3.

90. Shewmon, *supra* note 2, at 1775.

91. Botkin, *supra* note 34, at 254.

92. UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 338 (Supp. 1991).

93. UNIF. ANATOMICAL GIFT ACT, 8A U.L.A. 15 (Supp. 1989).

94. Botkin, *supra* note 34, at 252.

95. *Id.*

brain stem."⁹⁶ Both the Uniform Determination of Death Act and Florida Statute section 382.009 specify that brain death occurs only when there is *whole* brain death, including the death of the brain stem. In fact, all fifty states and the District of Columbia require a determination of whole brain death, including the death of the brain stem.⁹⁷ Furthermore, "[t]he Uniform Anatomical Gift Act clearly states that anatomic gifts can be made only after the donor has been declared dead."⁹⁸ Like the Uniform Determination of Death Act, this Act has also been adopted in all fifty states and the District of Columbia.⁹⁹ Because of these statutes, any use of anencephalic infants as organ donors, before the child meets the criteria of legal death, would be in violation of the law.

Whole brain death was determined by the President's Commission for the Study of Ethical Problems on Medicine and Biomedical and Behavioral Research as a "solid and objective standard on which virtually all lay individuals, physicians and philosophers could agree."¹⁰⁰ Whole brain death, therefore, serves as the optimal definition on which to base public policy in a pluralistic society. Although the President's Commission stated that parents, with the consultation of their physician, are the appropriate persons to decide upon treatment or non-treatment of severely defective newborns, the Commission stated that their decision would be limited because "they cannot choose a course of nontreatment that is 'clearly against the infant's best interests.'"¹⁰¹ Under the Uniform Determination of Death Act and Florida Statute section 382.009(1), an anencephalic infant is alive while the child exhibits residual brain stem activity. Because the Uniform Determination of Death Act has been adopted in all fifty states, the anencephalic child is deemed alive as long as residual brain stem activity is present. Removal of the infant's organs before cardiopulmonary death or total brain death would violate the Uniform Anatomical Gift Act's 'dead donor' rule.¹⁰² It would, therefore, constitute murder or infanticide under present law and the type of active euthanasia prohibited by the American medical community.¹⁰³

96. FLA. STAT. § 382.009(1) (1987).

97. Botkin, *supra* note 34, at 252.

98. *Id.*

99. *Id.*

100. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS ON MEDICINE & BIOMED. & BEHAV. RES., DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MED., & LEGAL ISSUES IN TREATMENT DECISIONS (1983).

101. Paliokis, *supra* note 14, at 212.

102. Brandon, *supra* note 60, at 792.

103. *Id.* (i.e. "active euthanasia involves direct action designed to kill [a] patient").

Because anencephalic infants have poor circulatory and respiratory systems, their organs deteriorate during their short lives. Consequently, the anencephalic infant, after reaching cardiopulmonary or whole brain death, is physiologically unsuitable for transplantation.¹⁰⁴

The problem with using anencephalic newborns as organ donors prior to satisfying a whole-brain death definition can be put in the simple form of a dilemma . . . if this individual is breathing, then he is either dead or he is not. If he is not dead, it seems rather important that we not remove his heart at this point in time. . . . Because the single most appropriate activity or duty that one has with respect to the dead is burial. If you genuinely believe that whole-brain death is a quibble, then you ought to be prepared to perform the rite of burial that is appropriate to the dead. . . . If you are not prepared emotionally to do that, then your mind hasn't convinced your gut yet, and I think that's the problem.¹⁰⁵

Judicial expansion or modification of the Uniform Determination of Death Act should be debated with the foresight that modification may not, ultimately, be limited to anencephalic infants. "The law adheres to what Judge Cardozo described as the 'tendency of a principle to expand itself to the limits of its logic.'¹⁰⁶ Including anencephalic infants within the Uniform Determination of Death Act might also be read to include other severely malformed infants who are born dying. These other conditions might include spina bifida, myelencephala, Trisomy 13, or hydrancephaly.¹⁰⁷ Additionally, "anesthesia is generally not used during organ removal from those considered brain dead under the Uniform Determination of Death Act. . . . [T]he potential for inflicting pain on the anencephalic infant is theoretically present."¹⁰⁸

The standard treatment for anencephalic newborns is "comfort care" only. Anencephalic babies are fed and kept warm, but no specialized treatment is given to prevent their early deaths.¹⁰⁹ An anencephalic

104. *Id.*

105. B. Freedman, MD, Discussion between Dr. Stiller, Dr. Girven and Dr. Freedman, 20 *TRANSPLANTATION PROC.* 64 (1988).

106. Leggans, *supra* note 54, at 460.

107. *Id.*

108. *Id.* at 461.

109. James W. Walter & Stephen Ashwal, *Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues*, 18 *HASTINGS CTR. REP.*, Oct.-Nov. 1988, at 19; see also Brandon, *supra* note 60, at 809.

infant's life span depends on the degree of progressive development of the brain stem and the medical and nursing care provided to the infant.

Although it is commonly stated that these infants [who survive birth] die within a few days of birth, various large studies and a number of anecdotal reports of longer survivals cast serious doubt on this contention . . . A review of the California Birth Cohort File between 1978 and 1982 revealed that of the 205 live born anencephalic infants with birthweight greater than 2,500 grams (and therefore of greatest interest *vis a vis* organs), 47 percent died within one day, an additional 44 percent between one day and one week, 8 percent between one week and one month, and 1 percent around three months of age. There are also documented cases of anencephalic infants living five and a half months, seven months, and fourteen months.¹¹⁰

Death is a gradual process. It does not come in a moment regardless of which organ ceases activity. The process of death "depends upon the resistance to the deprivation of oxygen that a given tissue or organ has, as to when it will, in fact, really die."¹¹¹ Artificial ventilation enhances the viability of the brain stem and prolongs brain death.

In 1987 and 1988, Loma Linda University Medical Center in Los Angeles, California, developed a protocol for twelve anencephalic infants. This protocol modified the standard medical treatment of "comfort care only" for anencephalic infants, and was administered to the infants whose parents initiated the request and gave informed consent.¹¹² Six of the infants were intubated at birth; the remaining six were intubated and offered intensive care when they appeared to be close to death.¹¹³ When intensive care was delayed until the infants were actually near death, their organs were not usable for transplantation.¹¹⁴ Dr. Joyce Peabody, the neonatologist in charge of the Loma Linda protocol, listed several of the medical findings on the twelve subject infants:¹¹⁵

110. Shewmon, *supra* note 5, at 15.

111. J. P. Girvin, *Brain Death Criteria-Current Approach to the Non-Ancephalic*, 20 *TRANSPLANTATION PROC.* 26, 26 (1988).

112. Peabody, *supra* note 66.

113. *Id.*

114. *Id.* at 349.

115. *Id.*

Table 5. Findings on Initial Neurologic Examination of All 12 Infants

Features	No. of Infants
1. Spontaneous Movement of Extremities	12
2. Exaggerated Sustained Response to Touch (startle myoclonus)	12
3. Suck, Root and Gag Response	
Present	7
Absent	5
4. Pupillary Response	
Fixed and Dilated	7
Fixed and Small	2
Reactive	3
5. Spontaneous Eye Movement	
Absent	8
Abnormal	4
6. Oculocephalic Response	
Absent	6
Abnormal	6
7. Funduscopic Examination	
Hypoplastic Optic Nerve	3
Not Seen	8
Normal	1
8. Corneal Response	
Absent	6
Present	6
9. Auditory Response (moro response to sound)	
Absent	7
Present	5
10. Tone	
Increased	8
Decreased	3
Normal	1
11. Deep Tendon Reflexes	
Increased	9
Decreased	3

12. Babinski Response	
Present	
Absent	2
	10
13. Spontaneous Respiration	
	12

Dr. Peabody's findings and observations in the twelve infants studied in the Loma Linda protocol suggested that the children's organs were "initially suitable" for transplantation, but lost that suitability as the dying process continued.

When steps were taken from birth for the full support and maintenance of the viability of transplantable organs, it appeared that the level of function of the organs could keep them suitable for donation. However, only one infant met the criteria for total brain death during full intensive care . . . [T]he provision of intensive care including maintenance of normal hydration, blood sugar, temperature, acid-base status, and oxygenation may interrupt the natural dying process. Modification of medical care prolonged the process of dying.¹¹⁶

Furthermore, the provision of modified medical care was limited to seven days for each of the twelve anencephalic infants studied.¹¹⁷ Two of the twelve anencephalic infants were diagnosed as brain dead during their respective seven day protocols and were therefore available as legal organ sources.¹¹⁸ No organs were extracted from the brain dead anencephalic infants because no donees were available to receive the organs.¹¹⁹

It is unlikely that the primary cause of death of these infants is progressive brain stem destruction or degeneration. . . . Theoretically, therefore, artificial ventilation and intensive care should help to preserve the integrity of the brain stem just as much as the other organs, and the only accomplishment would be to postpone the moment of death until some systematic complication were to supervene.¹²⁰

From the experience at Loma Linda, scientists have theorized that ventilation support to anencephalic neonates will prolong the infants' lives needlessly

116. *Id.*

117. Joyce L. Peabody, et. al., *Experience with Anencephalic Infants as Prospective Organ Donors*, 321 NEW ENG. J. MED. 344, 345 (1989).

118. *Id.* at 344.

119. *Id.* at 350.

<https://nsuworks.nova.edu/nlr/vol17/iss1/13>
Shewmon, *supra* note 5, at 15.

without significant benefit to another child.¹²¹

An *amicus curiae* brief was submitted to the Florida Supreme Court in the case regarding Baby Theresa.¹²² The brief was partially on behalf of six sets of parents of anencephalic children. The *amicus* filed the brief because of

a strong interest in protecting the lives and well being of persons with disabilities . . . [stating] any expansion of the criteria for determining death to include those persons who lack upper brain function (such as infants with anencephaly) will have a dangerous impact on living anencephalic children and all persons with mental disabilities who are unable to speak for themselves.¹²³

To stress the point that ancephalic babies can bring joy to their families, Mrs. Nelms brought Keyahana to the oral argument of this case in the Florida Supreme Court, and Mrs. Flint attended the argument with her daughter, Kimberly. Mrs. Andis attended with pictures of her daughter, Emma Nicole, and reported that she had been subject to pressure from doctors, family members and acquaintances to abort Emma Nicole after she had learned of her daughter's condition in the sixteenth week of pregnancy. She and her husband decided to give birth to their daughter at home, and she stated that her life, her husband's life, and the lives of her two other children were enhanced by Emma Nicole's birth and her life of five days.

VI. BEHAVIORS AND LIFE EXPECTANCY OF ANENCEPHALIC INFANTS

Baby Theresa appeared to be a normal baby with a cap covering the skull lesion on the top of her head. She had independent cardiorespiratory function. She appeared to respond to pain stimuli. She sucked. She moved

121. Shewmon, *supra* note 2, at 1779.

122. Brief for *Amicus Curiae*, National Legal Center for the Medically Dependent and Disabled, Inc., *In re T.A.C.P.*, (No. 79-582). Paul and Laura Flint of Jacksonville, Florida, parents of surviving three year old Kimberly; Martina and Bob Bailey of Lindenhurst, New York, parents of surviving eleven year old Cara Lynn; Kerry and Alva Nelms of Temple, Texas, parents of three month old Keyahana; Anne and Davis Andis of Spring, Texas, parents of Emma Nicole who survived five days after birth; Kristina and Richard Fox II of Falmouth, Virginia, parents of Gabrielle, who survived twenty-five hours after birth; and Jennifer and James Molnar, M.D., of Cincinnati, Ohio, parents of Jeremy, who survived three days after birth.

her arms and legs. Baby Theresa appeared to be alive to all who saw her.¹²⁴

An anencephalic baby who survives the birth trauma usually has a well-developed brain stem. The brain stem is a critical portion of the brain: it sustains respiration, circulation and many other indicia of life. Although anencephalic infants may lack a whole brain, those who have developed relatively normal brain stems exhibit fairly typical newborn behaviors.¹²⁵

The behavior of an anencephalic newborn is frequently similar to that of a normal infant. An anencephalic infant with a developed brain stem will exhibit typical newborn behaviors such as "purposeless back-and-forth movements of the extremities, sucking and swallowing, normal orofacial expressions to gustatory stimuli, crying, withdrawal from noxious stimuli and wake/sleep cycles."¹²⁶

A live born anencephalic infant exhibits a heartbeat, brain stem and respiratory functions, and may exhibit "eye movements, pupillary responses to light, spontaneous or induced movements of the face, limbs, or digits, including reflex swallowing, and . . . corneal, gag, cough, sucking and rooting reflexes."¹²⁷ Based on all of these life-indicating factors, Baby Theresa, and other anencephalic infants, under the present law, are not legally dead merely because they suffer from anencephaly. Anencephalic or other decerebrate human newborns "with relatively intact brain stems can manifest a surprising repertory of complex behaviors, including distinguishing their mothers from others, consolability, conditioning and associative learning."¹²⁸ In normal human newborns, even though the cerebral cortex is present, the upper brain is "much less developed microscopically than the brain stem, and the cerebral cortex is relatively nonfunctional."¹²⁹ Decerebrate infants are, therefore, neurologically more similar to normal infants than to decerebrate adults, and thus, anencephalic infants appear to function similarly to normal newborns.¹³⁰ Consequently, it neither logically nor physiologically follows that anencephalic infants cannot feel pain. The

124. Baby Theresa was placed on a mechanical respirator on two occasions in order to extend her life span while the lawsuit to get court permission to harvest her organs was pending. She breathed without assistance before and after each mechanical ventilation period.

125. Shewmon, *supra* note 5, at 18.

126. *Id.* at 13.

127. Aubrey Milunsky, *Harvesting Organs for Transplantation From Dying Anencephalic Infants*, 82 PEDIATRICS 274, 275 (1988).

128. Shewmon, *supra* note 2, at 1776.

129. *Id.*

130. *Id.*

difference between normal and decerebrate infants is not so much in their actual functional abilities, as in their potential for future cognitive development. "[B]oth prudence and logical consistency demand that society attribute to anencephalic infants at least as much consciousness and capacity for suffering as we attribute to laboratory animals with even smaller brains, which everyone seems to feel obligated to treat 'humanely.'"¹³¹

Pregnancy with an anencephalic fetus puts both the mother and fetus at greater risk. Studies indicate that other fetal congenital malformations than anencephaly occur in thirteen percent to forty-one percent of the fetuses and that approximately sixty-five percent of anencephalic fetuses die in utero.¹³² A live born anencephalic infant tends to be born prematurely, with a low birth weight.¹³³ Additional risk to the infant occurs during labor and natural birth "because of trauma to the exposed cranial lesion and ischemia from premature separation of the placenta."¹³⁴ As stated previously, caesarian delivery is contraindicated because of increased risk to the mother.¹³⁵

In Sheffield, England, where the natural incidence of anencephaly is six per 1,000 births, almost twenty times higher than that of the United States, the incidence of live born anencephalic infants was reduced "40 fold over a 12 year period" due to the rise of antenatal screening programs and the subsequent terminations of anencephalic pregnancies.¹³⁶ Furthermore,

In Massachusetts from 1972 through 1975, forty-seven percent of the anencephalic infants were live-born, fifty-three percent were stillborn, and there were no induced abortions; in the two years 1986 and 1987, after the introduction of prenatal screening, the distribution was three percent live-born, seven percent stillborn, and ninety percent aborted. In the California state screening program, 243 fetuses with anencephaly were identified through June 1988, and for 230 pregnancies, in the outcomes which are known: induced abortions in seventy-nine percent, live births in eleven percent and stillbirths in ten percent.¹³⁷

131. *Id.*

132. Medical Task Force on Anencephaly, *supra* note 25, at 669-70.

133. *Id.*

134. *Id.* at 670.

135. *Id.*

136. *Id.* at 671.

137. Task Force on Anencephaly, *supra* note 25, at 671; *see also* Lorber J. Ward, *Spina Bifida-A Vanishing Nightmare?*, 60 ARCH. DIS. CHILD 1086-91 (1985); D. N. Medearis & L. B. Holmes, *Anencephalic Infants as Organ Donors: Two Unaddressed Issues*, 45 AM. J. HUM. GENETICS A54 (1989).

In the studies of anencephalic infants who survived birth, the "uniform imminence of their death" seems to be subject to question.

In one series, 5% lived between 1 and 2 weeks. Another study found that, of those with a birth weight greater than 2500 grams (and therefore of greater interest vis-a-vis organs), 8% survived between 1 week and 1 month and 1% lived up to 3 months. In addition, there are documented cases of anencephalic infants surviving 16 days, "several weeks," 32 days, 51 days, 2 months, 85 days, 5 1/2 months, 7 months and 14 months.¹³⁸

In conclusion, live born anencephalic infants who have a developed brain stem behave similarly to normal infants who have not yet developed the use of a functional cerebral cortex. Both anencephalic and normal infants have brain stems which sustain respiration, circulation and other indicia of life. Most live born anencephalic infants die before they are two weeks old. However, increased prenatal care and alpha-fetoprotein screening will increase the incidence of second trimester abortion and decrease the rate of live born anencephalic infants.

VII. DONATION VS. PROCUREMENT: THE PARENT'S RIGHTS VS. THE CHILD'S RIGHTS

Although some authorities have opined that the anencephalic infant does not experience any pain, the potential for inflicting pain on the anencephalic infant is recognized throughout the medical literature. Omar Costa, M.D., one of Baby Theresa's neonatologists at Broward General Medical Center, in Fort Lauderdale, Florida, stated, in an affidavit filed with the initial petition filed by the parents, that Baby Theresa "[was] currently

138. Shewmon, *supra* note 2, at 1778; see also J. MARK ELWOOD & JOHN HAROLD ELWOOD, EPIDEMIOLOGY OF ANENCEPHALUS AND SPINA BIFIDA 87-90 (1980); JEFFREY J. POMERANCE, ET AL., ANENCEPHALIC INFANTS: LIFE EXPECTANCY AND ORGAN DONATION; F. Graham, et al., *Precocious Cardiac Orienting in a Human Anencephalic Infant* 199 SCIENCE 322-24 (1978); RONALD J. LEMIRE, ET AL., NORMAL AND ABNORMAL DEVELOPMENT OF THE HUMAN NERVOUS SYSTEM 62 (1975); JOSEF WARKANY, CONGENITAL MALFORMATIONS 199 (1971); Diane Gianelli, *Anencephalic Heart Donor Creates New Ethics Debate*, 3 AM. MED. NEWS 47-49 (1987); J. Nielson & R. Sedgwick, *Instincts and Emotions in an Anencephalic Monster*, 110 J. NERV. MENT. DIS. 387-94 (1949); J. Pomerance & B. Schifrin, *Anencephaly and the "Baby Doe" Regulations*, 21 PEDIATRIC RES. 373A (1987).

in a great deal of pain and discomfort."¹³⁹ Furthermore, the Loma Linda protocol regarding anencephalic infants was subject to dissatisfaction from the medical community, in part because of the lack of pain medications to the infants. "The grimaces and crying of these children have convinced some physicians they can feel pain."¹⁴⁰ In fact, because of these theories, Demerol and Narcan were proposed to be administered to newborn anencephalic infants exhibiting signs of distress.¹⁴¹

As stated previously, anesthesia is generally not used during organ removal from those patients, including anencephalic infants, who are considered brain dead under the Uniform Determination of Death Act's whole brain definition of death. Anencephalic infants would still have some brain activity during organ removal under the proposed scheme to modify Florida Statute section 382.009 or to declare the anencephalic child legally dead. Thus, the potential for inflicting pain on the anencephalic infant while removing the child's organs is theoretically present.¹⁴²

Because anencephalic infants are not capable of a voluntary, freely chosen act, they are incapable of making a "donation." They are incapable of consenting, as is anyone incapable of consenting to donate an organ which will end his life. They also fail to meet another additional criteria of organ donation: these children have no interest in saving the life of the prospective recipient. Consequently, "it is more appropriate to refer to them as sources rather than donors, and to the taking of their organs for transplantation as removal or procurement rather than donation."¹⁴³ Additionally, it is depersonalizing to refer to these children by terms such as "anencephalics" or "sources." These infants are more accurately described as "infants from whom organs might be taken," or to be more precise, the word "donor" or "sources" may be placed in quotation marks.¹⁴⁴

In point of fact, the anencephalic infant is not doing the giving, or

139. Answer Brief of Guardian Ad Litem, at app. A, ¶ 11, *In re T.A.C.P.* (No. 79582) (Fla. 1992). The two other consulting physicians at Broward General Medical Center, Department of Neonatology, treating Baby Theresa were Dr. Richard Beach and Dr. Atiah Hussain. Dr. Beach stated in another affidavit filed with the parent's initial petition that in his opinion, he could not "state whether or not patient, Theresa Campo, [was] ... experiencing pain or discomfort within a reasonable degree of medical certainty." Dr. Hussain stated, in his affidavit, that "patient, Theresa Campo, [was] not experiencing pain or discomfort."

140. Friedman, *supra* note 14, at 932-33 n.78.

141. *Id.* at 933

142. Leggans, *supra* note 53, at 460-61.

143. Fost, *supra* note 19, at 6.

144. *Id.*

"donating" of his or her organs. Instead, the child's parents are seeking to harvest the infant's organs. Some parents may be motivated by altruism, but not all altruistic behavior is good.

Altruism describes only what motivates an action, not its style, form, content or outcome. Actions can be well motivated and selfless, but still self deceptive, ill advised, reactive, foolhardy, inappropriate, or destructive. In short, it is no contradiction to say of actions that they are motivated by altruism, but on the whole morally unjustified.¹⁴⁵

By seeking to transplant their anencephalic infants' organs into another child, parents are seeking a way of providing some meaning into the birth of their child and assuaging the parental grief. However, it is not the parents who are the patients.

The assumption of a therapeutic meaning for parents, while having some clinical precedent-is not the main question-and to emphasize it only confuses the issue. Care must be taken to avoid putting the parental grief process in the center of the picture, for it all too easily displaces the infant from the focus of attention.¹⁴⁶

Of equal importance, one must remember that the parent who seeks to "donate" his child's organs could not donate his own vital organs at the expense of his own life, no matter what his prognosis might be. Therefore, the question remains: How can a parent "donate" his child's organs if he could not donate his own vital organs in similar circumstances?

As stated previously, parents who seek to "donate" the organs of an anencephalic child may be motivated by altruism, or they may be motivated by "ambivalence, depression, hidden problems, fear, erroneous perceptions, and misconceptions."¹⁴⁷ However, should the parents who seek to "donate" their anencephalic child's organs, and thus, hasten their child's death, be subject to scrutiny themselves? Assuming *arguendo* that parents could make this decision to terminate their child's breathing and circulation in order to provide an organ source for another handicapped child, what qualifications or guidelines should the state formulate to decide which parents should be allowed to make these decisions? Would any parents by virtue of their parenthood qualify, or should the parents be free of abuse or neglect adjudications against them regarding any of their other children?

145. Churchill & Pinkus, *supra* note 11, at 156.

146. *Id.*

147. *Id.*

During a *Point-CounterPoint* radio talk show which took place at the time the Loma Linda protocol was being utilized, the subject of harvesting the organs of anencephalic infants was discussed. "[T]he mother of a 12-year-old vegetative child called in to say that she would have no qualms about offering her child's organs to benefit another child, if only it were legal."¹⁴⁸ Parents in the contemporary United States possess a somewhat circumscribed right of parental autonomy which has been developed under constitutional principles of religious freedom, due process and the right of privacy. However, the parents rights are not unlimited. A newborn infant in the United States is also under the *parens patriae* power of the State, which gives the State standing to protect the health, comfort and welfare of its citizens, including the children. The State has the power to punish a parent who abuses or neglects a child, and to remove that child from the parent's care, if necessary. The Court may prosecute and punish those persons who harm a child. The Court can appoint a guardian when it appears "the parents are incapable of making decisions concerning their children, or if the parents' choice conveys a disregard for their child's welfare."¹⁴⁹ Furthermore, Florida courts have long recognized that the rights of parents are "subject to the overriding principle that it is the ultimate welfare or best interest of the child which must prevail."¹⁵⁰

The parents of an anencephalic child may authorize the non-treatment their anencephalic newborn. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended that parents of anencephalic infants be authorized to reject "clearly futile therapies" for their newborns.¹⁵¹ Interestingly, the 1984 amendments to the federal Child Abuse Prevention and Treatment Act¹⁵² provided three exceptions to the withholding of medically-indicated treatment from handicapped infants—all of which apply to anencephalic infants. Those exceptions included: 1) the infant was chronically and irreversibly comatose; 2) the provision of such treatment would (a) merely prolong dying, (b) not be effective in ameliorating or correcting all of the infant's life threatening conditions, or (c) otherwise be futile in terms of the survival of the infant; or 3) the provision of such treatment would be

148. Shewmon, *supra* note 2, at 1777 (quoting *Point-CounterPoint*, (KABC radio broadcast, Feb. 20, 1988)).

149. Brandon, *supra* note 60, at 810-11.

150. *In re Camm*, 294 So. 2d 318, 320 (Fla. 1974).

151. Brandon, *supra* note 60, at 814.

152. Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5106H (1988).

virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.¹⁵³

In this case, the parents sought to end their daughter's life in order to procure her organs. No legal authority supports the parents' autonomy in terminating their daughter's life. In fact, the United States Supreme Court has previously held:

And neither rights of religion nor rights of parenthood are beyond limitation. Acting to guard the general interest in youth's well being, the state as *parens patriae* may restrict the parents control by requiring school attendance, regulating or prohibiting the child's labor and in many other ways. Its authority is not nullified merely because the parent grounds his claim to control the child's course of conduct on religion or conscience. Thus, he cannot claim freedom from compulsory vaccination for the child more than for himself on religious grounds. The right to practice religion does not include liberty to expose the community or the child to communicable diseases or the latter to ill health or death.¹⁵⁴

Furthermore, it is questionable whether the mother of an anencephalic child could abort the child in the third trimester of the pregnancy; Baby Theresa's parents did not find out about her condition until the eighth month of pregnancy. Termination earlier than in the third trimester is available after alpha-fetoprotein screening in the sixteenth week.¹⁵⁵ The attorneys representing Baby Theresa's parents had alleged that the parents had the legal authority to terminate the pregnancy, had they so chosen to pursue that avenue. However, Florida Statute section 390.001 (Termination of Pregnancies) places strict control over termination in the last trimester, and consequently, it is unknown whether Baby Theresa's mother would have been able to terminate her pregnancy in the third trimester.¹⁵⁶ Clearly,

153. *Id.* § 5106G(10)(c).

154. *Prince v. Massachusetts*, 321 U.S. 158, 166-67 (1943).

155. See FLA. STAT. § 390.001 (1980); FLA. STAT. § 797.03(3) (1978).

156. See FLA. STAT. § 390.001(2)(a) (1980). This section provides:

(2) Termination in last trimester, when allowed.—No termination of pregnancy shall be performed on any human being in the last trimester of pregnancy unless:

(a) Two physicians certify in writing to the fact that, to a reasonable degree of medical probability, the termination of pregnancy is necessary to save the life or preserve the health of the pregnant woman.

Id.

there is no absolute right to an abortion in the third trimester and Baby Theresa's parents, even faced with the knowledge that their child was to be born with the condition of anencephaly, could not be guaranteed an abortion. Parents of anencephalic fetuses must meet the criteria of the abortion statute, just as the criteria for the brain death statute must be met before Baby Theresa's organs may be harvested.

VIII. PERSON VS. NON-PERSON: INFANTICIDE VS. HARVESTING

In order to deprive an anencephalic human infant of the protections afforded the child under the state and federal constitutions, and under the fifty states' various determination of death and anatomical gift acts, as well as all other relevant law, an anencephalic infant would necessarily have to be defined as a "non-person" and removed from the category of "personhood," which protects all humans under the jurisdiction of the United States and the several states. In other words, only "persons" are afforded the protection of the constitutions and the laws. If non-persons were so labeled, and exempted from "personhood," their categorization could exclude them from legal protections against murder, infanticide and euthanasia.

Personhood, then, is a moral category that denotes the limits of justifiable termination of life. If an entity, regardless of its age or maturity, can meet the requirement of personhood, its life is given moral protection from arbitrary and indiscriminate destruction. If, in contrast, an entity cannot claim the status of a person, its continued existence is tenuous because it has no serious right to life.¹⁵⁷

The use of an anencephalic infant as a solid organ source for kidney, heart and liver transplants is motivated by the need of chronically and terminally ill infants, children and adults for organ transplants, and by the concept that "donation" of the anencephalic infant's organs is therapeutic to the birth parents. Motivation for the redefinition of death and personhood "does not spring from any merit intrinsic to the question," nor from an interest in the anencephalic infant.¹⁵⁸ Instead, motivation arises from a need for solid organs which may be partially served by taking them from the

157. ROBERT F. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE 152 (1984); see also HELGA KUHSCH & PETER SINGER, SHOULD THE BABY LIVE? 90-177 (1985).

158. Churchill & Pincus, *supra* note 11, at 162.

anencephalic child.¹⁵⁹ Should some members of society not have another use in mind for an anencephalic infant, questions regarding a redefinition of death and personhood would be academic.¹⁶⁰

Somatic death caused by cardiorespiratory failure is not compatible with organ donation because of the gradual deterioration of the solid organs due to the insufficient passage of blood and lymphatic fluid. In order to provide viable organs to the donee, brain death must occur prior to cardiorespiratory collapse.¹⁶¹

Advocates of utilizing the solid organs of the anencephalic infant for transplantation before whole brain death argue that the anencephalic infant is "brain absent" and lacks the capacity to achieve higher cortical function. Because higher cortical function regulates human consciousness, they argue that there is no "awareness" in the anencephalic infant; therefore, "there are no intrinsic interests of anencephalics to be defended."¹⁶²

Another proposal for the redefinition of whole brain death comes from the utilitarian theory that brain death or death itself should be defined in whatever way maximizes the greater good: the maximization of the "net utility for society as a whole."¹⁶³ Another argument suggests that the "inevitability of the rapid demise of anencephalics justifies their use ante mortem."¹⁶⁴ Furthermore, it has been argued, the short natural life span of an anencephalic infant precludes the usual bonding with parents and staff. "[T]hus, a prompt unnatural death . . . would produce no additional harm to parents or staff."¹⁶⁵

Some commentators argue that anencephalic infants should bypass the whole brain death criteria because:

[A]nencephaly 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 in a class that is entirely *sui generis*, and one for which special rules and laws should apply.¹⁶⁶

159. *Id.*

160. *Id.*

161. *Fost, supra* note 19, at 6.

162. The Ethics and Social Impact Committee of the Transplant Policy Center, *Anencephalic Infants as Sources of Transplantable Organs*, 18 HASTINGS CTR. REP. Oct.-Nov. 1988, at 28, 29 [hereinafter *Ethics Committee*].

163. *Shewmon, supra* note 2, at 1774.

164. *Id.*

165. *Botkin, supra* note 34, at 253.

166. *Ethics Committee, supra* note 162, at 28.

The most pervasive of the arguments, and the ultimate basis for the previously enumerated arguments for organ harvesting, labels anencephalic infants as "non-persons." In this philosophical theory, only beings capable of sapient life have the rights and privileges of "personhood." If anencephalic newborns are non-persons, one could perhaps justify using them as mere "means" for the benefit of other persons.¹⁶⁷ The rationale that a live born human being can be a non-person is derived from the infant's lack of a forebrain, "which gives rise to characteristic human activity . . . [such as] self awareness, cognitive function [and] ability to communicate."¹⁶⁸ This theory eliminates the newborn non-persons from the protections of the Uniform Determination of Death Act, and could allow legal abortion and utilization of the organs at any time prior to or after delivery. Joseph Fletcher, a noted philosopher and author of *Indicators of Humanhood: A Tentative Profile of Man*,¹⁶⁹ argued in 1972 that any human being who falls below a forty I.Q. is "questionably a person; below the 20 mark, not a person This has bearing, obviously, on decision-making in gynecology, obstetrics and pediatrics, as well as in general surgery and medicine."¹⁷⁰

Harvesting organs from a newborn anencephalic infant "may eventually lead to similar procedures or experimentation with other dying patients, or perhaps even non-dying patients whose lives appear to have little value."¹⁷¹ In opposition to the "expedient" theory postulated by proponents of organ harvesting from live born anencephalic infants, Judeo-Christian ethics, the root of western medical and legal ethics, have "a strong prohibition against the taking of innocent human life, no matter how great the benefit to others. The justification for this prohibition derives from God."¹⁷²

The uniform prognosis of early mortality is not unique to anencephalic infants: Potter's syndrome and Trisomy 13 also qualify. Additionally, more reliable prenatal diagnosis will reduce the incidence of anencephalic newborns consequent to the option of second trimester abortion. If anencephalic infants are not available, then an argument may be made to include other infants "with conditions such as holoprosencephaly, hydren-

167. Arras & Shinnar, *supra* note 10, at 2284-85.

168. Leggans, *supra* note 53, at 454-55.

169. J. Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, 2 HASTINGS CTR. REP. 1 (1972).

170. *Id.*; see also Shewmon, *supra* note 2, at 1776.

171. Botkin, *supra* note 34, at 82.

172. *Id.*

cephaly, and certain trisomies as well as adults in permanent vegetative states.¹⁷³

In *Roe v. Wade*,¹⁷⁴ some of the amici argued that the fetus was a "person" within the language and meaning of the Fourteenth Amendment. If this suggestion of personhood had been established, the other side of the argument would have collapsed and the fetus' right to life would then have been guaranteed specifically by the Fourteenth Amendment.¹⁷⁵ The United States Supreme Court mandated that "live birth" be the accepted criterion for recognition as a person.¹⁷⁶ "The law has drawn an arbitrary line . . . at the moment of birth to distinguish between abortion and infanticide and has granted the abnormal newborn more protection than the abnormal fetus."¹⁷⁷ If an anencephalic newborn were subsequently defined as a non-person by a court or legislature, the anencephalic infant would arguably have no legal protection under the state and federal constitutions, and the Fourteenth Amendment; the child's organs could then be harvested and his life be terminated without liability.¹⁷⁸

In *Day v. Nationwide Mutual Insurance Co.*,¹⁷⁹ the Florida Third District Court of Appeal held: "A child injured before birth and born alive is a person under the Florida and Federal Constitutions. As such, that person is entitled to all of the constitutional rights, privileges and protections afforded to all other persons."¹⁸⁰

To deem anencephalic infants "non-persons" would be to define out of existence a class of handicapped human beings. If anencephalic infants are placed in a special category of "non-persons," other human beings could also slip down a slippery slope into non-personhood, either to expand the organ donor pool or for other utilitarian purposes. Severely retarded persons, persistent vegetative state persons and other severely disabled infants may become candidates for that special category. Prudence also requires the acknowledgement that anencephalic infants could not in any way satisfy the yearly demand for solid organs.¹⁸¹

173. Arras & Shlomo, *supra* note 10, at 2285.

174. 410 U.S. 113 (1973).

175. *Id.* at 156-57.

176. *Id.* at 158.

177. Paliokas, *supra* note 14, at 227-28.

178. *Id.* at 227 (citation omitted).

179. 328 So. 2d 560 (Fla. 3d Dist. Ct. App. 1976).

180. *Id.* at 562.

181. Law Reform Comm'n of Canada, *Procurement and Transfer of Human Tissues and Organs*, in WORKING PAPER 66 (1992).

Denial of personhood could "degrade the pregnancy and establish an environment where the parents of anencephalic infants, and the infants, might be denied the respect ordinarily given other infants and parents."¹⁸² Under the common law over the past centuries, the birth of a human being has been acknowledged to create a person who is under the protection of the common law.¹⁸³

Whether an anencephalic infant is a "person" depends upon the basis of the definition. A biological basis for personhood would admit the anencephalic child. A basis requiring cogitation, social interaction, rationality, self-consciousness and desires about the future would eliminate the anencephalic neonate from the category. Unfortunately, the second set of criteria would also eliminate a multitude of other persons with whom we interact with every day: persons whom we do not question are "persons" with rights and privileges. As Justice Holmes observed, "where to draw the line . . . is the question in pretty much everything worth arguing in the law."¹⁸⁴

The argument that "whole brain death" should be replaced by the higher brain standard of brain death was considered and rejected by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in a 1981 report which "expressly rejected the 'higher brain' formulations of death . . . and favored the whole brain death criteria."¹⁸⁵ Furthermore, the Commission

did not consider prognostic uncertainty to be an important factor in their advocacy of the whole brain death criteria The moral significance of brain stem function is that (1) it serves as the principal source of integration for vital physiologic processes and (2) perhaps more important from a public policy standpoint, it produces sufficient activity in individuals to support the appearance of being alive by our basic, intuitive criteria. These patients breathe spontaneously, they may have sleep-wake cycles with eye opening and movement, and they may yawn and have reflex motor activity The moral intuition of many dictates that such patients be treated as any other impaired but living individual.¹⁸⁶

182. Leggans, *supra* note 169, at 456.

183. *Id.* at 456; see also U.S. NAT'L COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMED. & BEHAV. RES., RES. ON THE FETUS 12-13 (1975).

184. Friedman, *supra* note 14, at 954-57; see also Sissela Bok, *Ethical Abortions*, 2 HASTINGS CTR. REP. Apr.-May 1974, at 33, n.273 (1974).

185. Brandon, *supra* note 60, at 800.

186. Botkin, *supra* note 34, at 250.

Basically, "[d]eath should not be a diagnosis of convenience, and anencephalic infants should not be considered dead until they are dead."¹⁸⁷ In this case, a definition of legal personhood for the anencephalic infant would preserve society's commitment to the life of the human newborn and to the lives of the most seriously handicapped.

The prognosis of impending death is made for many non-anencephalic patients "who are almost, but not quite, brain dead, yet that does not justify diagnostic corner cutting or proceeding with organ harvesting before actual death in those patients."¹⁸⁸ The high standards demanded by the medical profession and society in general should not be eroded because of a shortage of transplant organs.¹⁸⁹ To a significant portion of the United States population, a live born anencephalic infant is a living human being and has the same constitutional rights as any other person.

[I]t would be presumptuous for anyone to maintain that he or she was certain enough that an anencephalic infant was not a person to be willing to risk committing murder by killing it for the organs, given that a large number of equally intelligent people do regard it as a person, albeit with a severe disability.¹⁹⁰

If newborn anencephalics are regarded as human beings with fewer rights, or as "non-persons," the lack of personhood may justify harvesting their organs and the early termination of their lives. The weakest members of society are the most vulnerable to the utilitarian approach, since the weakest members are powerless and "useless," in economic terms at least. Anencephalic infants are arguably exceptions to the whole brain death rule because they are weak, will not survive, and it is expedient to harvest their organs. However, personhood has never been defined as contingent upon the size of one's brain, one's life expectancy or whether "certain nerves and muscles work."¹⁹¹ The suggestion that anencephalic infants may not be persons indicates that the community to which we belong may not be open to the weak and the most seriously handicapped. The exclusion from personhood is "rather because we have some use in mind for them."¹⁹²

187. *Id.*

188. Shewmon, *supra* note 2, at 1779.

189. *Id.*

190. *Id.* at 1776.

191. Alison Davis, *The Status of Anencephalic Babies: Should Their Babies Be Used as Donor Banks?*, 14 J. MED. ETHICS 150, 152 (1988).

192. Churchill & Rosa, *supra* note 11, at 162-63.

Should it be possible to disqualify a living human being from personhood based upon a neurological defect, a disability or a hardship, the practice of disqualifying persons would be fraught with error. Where should the line be drawn along the continuum of severity? In harvesting organs from a pre-whole brain death anencephalic infant, if the harvester believed he was killing a non-person for the sake of a person, "the majority of the rest of the world in their inevitable unsophistication may fail to perceive any distinction between that and [infanticide] justified by utilitarian principles The general impression that the latter had become legitimate [c]ould have disastrous consequences for society."¹⁹³

The dilemma of harvesting a "non-person's" organs for the benefit of a "person" defies explanation. Why should an infant with one defective organ be labelled a "non-person" and sacrificed for another infant with a different defective organ who is labelled a "person?" Legalistic arguments revolving around "person" vs. "non-person" are made in order to avoid the constitutional protections afforded "persons." Before distinguishing "person" from "non-person", in regard to the defective infant, we may consider that humankind has a history of eliminating from its membership unpopular groups such as slaves, witches and wartime enemies. "To question someone's humanity or personhood is the first step towards mistreatment and killing."¹⁹⁴

The resolution of the question whether an anencephalic infant is a person or a non-person determines whether taking her organs prior to cardiopulmonary or whole brain death is infanticide or harvesting. Exempting a handicapped infant from the personhood category in order to obtain human organs may be seen by some intelligent persons as the appropriate use for a decerebrate child, and by other equally intelligent persons as infanticide or murder.

IX. THE BIOETHICAL POSITION OF CHILDREN

"[T]he history of childhood is a nightmare from which we have only recently begun to awake."¹⁹⁵ Child abuse has been historically documented through recorded history. Even easier to document has been the widespread and tolerated practice of infanticide. The unprotected status of

193. Shewmon, *supra* note 2, at 1776.

194. John Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 *Stanford L. Rev.* 213, 247 (1975); *see also* Bok, *supra* note 184, at 41.

195. FLOYD DEMAUSE, *THE HISTORY OF CHILDHOOD* (1974).

infants and children made infanticide commonplace. In seventeenth century China, thousands of babies were thrown on the street like refuse each day. In the nineteenth century, foundling homes were established for unwanted infants in cities and towns such as London, Paris and St. Petersburg. These foundling homes admitted up to 5,000 infants each year. Few of those children survived the "socially acceptable death sentence" of being placed in a foundling home.¹⁹⁶ In London, at the time of Disraeli, the "police seemed to think no more of finding a dead child than of finding a dead dog or cat."¹⁹⁷ By the middle of the 20th century, "social acceptance of active killing of normal children had all but disappeared from Western societies, but passive euthanasia of infants with birth defects [was] still openly practice[d] in England and in the United States."¹⁹⁸

The ancient Hebrews accepted infanticide as a religious offering and as a sign of religious obedience. The Bedouins' tribal life permitted the destruction of infants, particularly girls or the malformed. Eskimos only recently have moved away from the tradition of abandoning infants to freeze when it was decided that the tribe could not support them. Polynesian tribes had a custom of eliminating all children after the birth of third or fourth child. Australian aborigines killed, by starvation or exposure, any infant who could not be carried on a long march. The ancient peoples of China and India practiced infanticide particularly on female infants to control family size and because females were devalued. Serious questions regarding infanticide in modern China and India are frequently raised with the limitations on family size in China and the devaluation of females in both China and India. In ancient Greece, classical Rome, renaissance Italy and Western European societies have all practiced infanticide on unwanted or handicapped infants with little repercussions. In England during the 19th century, infanticide was known as "the great social evil of the day."¹⁹⁹

Infanticide has historically been motivated by economic reasons: from a dead child representing one less mouth to feed, to social pressures such as illegitimacy or the devaluation of birth in some societies. Other infanticides occur because of the abnormality of the infants, thought to be the work of the devil or monsters produced from bestial sexual activities. The chance

196. *Id.*

197. W. Reich, I ENCYCLOPEDIA OF BIOETHICS 151 (1978); see also DEMAUSE, *supra* note 195; William L. Fanger, *Infanticide: A Historical Survey*, HISTORY OF CHILDHOOD Q. 353-88 (1974); Raymond A. Duff & A. Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED 890-94 ().

198. *Id.*

199. WEIR, *supra* note 157, at 5-15.

of an infant surviving was increased if he were male, legitimate according to the social mores, a member of the religious or racial majority and apparently normal in appearance. The chance of surviving infanticide decreased if the child were a female, a bastard, a minority group member or anomalous.²⁰⁰ Infanticide has been thought morally justifiable by some societies because newborns, in their estimation, do not qualify as persons.²⁰¹

In the United States in the 20th century, dying children, whose conditions are such that treatment is useless, are protected from unnecessary treatment. Prolonging the dying process through intubation and other physically invasive acts administered to the dying child in order to preserve his organs has no benefit to the anencephalic child; the only benefit which may be had is a potential benefit to a possible recipient of the solid organs. To prolong the anencephalic child's dying is in contravention of the National Child Abuse Prevention and Treatment Act.²⁰² Additionally, the President's Commission for the Study of Ethical Problems on Medicine and Biomedical and Behavioral Research recommended that "clearly futile therapies" be rejected for these neonates.²⁰³

Because life support is rarely administered to anencephalic neonates, a ventilation program for newborn anencephalic children would probably be considered "research" rather than "treatment."

The first principle of the 1949 Nuremberg Code prohibited involving children in research The National Commission for the Protection of Human Subjects of Biomedical or Behavioral Research, established in 1974 to "identify the requirements for informed consent to participation in . . . research by children, prisoners, and the institutionalized mentally infirm . . . [which made] recommendations [to] the Department of Health and Human Services [who] published regulations in 1983 providing additional protections for children involved as subjects in research."²⁰⁴

200. *Id.* at 17-20.

201. *Id.*

202. See Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5106H (1988).

203. James W. Walters & Stephen Ashwal, *Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues*, 18 HASTINGS CTR. REP. Oct.-Nov 1988, at 19, 20-21; see also PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS ON MEDICINE & BIOMED. & BEHAV. RES., DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MED., & LEGAL ISSUES IN TREATMENT DECISIONS (1983).

204. Brandon, *supra* note 60, at 814-15.

Informed parental consent does not permit a child to be a research subject.²⁰⁵ Research with children as subjects is "under the scrutiny of institutional or hospital review boards which demand, among other requirements, minimal risk to the child" in accordance with sound ethical principles.²⁰⁶

In Florida, Representative Bloom filed House Bill 1089 on April 5, 1988, proposing that the following language be added to section 382.009 of the Florida Statutes:

However, when anencephalia exists, it is presumed brain activity does not exist and the criteria for brain death have been fulfilled. "Anencephalia" is defined as a developmental anomaly characterized by absence of the cranial vault, and cerebral hemispheres completely missing or reduced to small masses attached to the base of the skull.²⁰⁷

The bill died in the Committee on Health and Rehabilitative Services on June 7, 1988.²⁰⁸ Thus, it is important to note that the Florida Legislature refused to accept the specific changes necessary to harvest Baby Theresa's organs.

X. PROTECTIONS UNDER THE LAW

The decision whether Baby Theresa or other anencephalic infants may be utilized as organ sources ultimately rests with the highest courts in the United States. Should Baby Theresa's personhood be established by the Florida Supreme Court, she would be subject to the various protections of the Florida and United States constitutions.²⁰⁹ Should Baby Theresa be declared a "non-person," the following constitutional protections would be denied to her, other anencephalic infants, and possibly to other handicapped human beings.

205. *Id.* at 815.

206. *Id.* at 814-16.

207. Fla. H.R. 1089, Reg. Sess., 1988.

208. JOINT LEGIS. MGMT. COMMITTEE, FLA. LEGIS. FINAL LEGIS. BILL INFO., 374 (1988).

209. The United States Constitution contains no definition of "person" and no discussion of the right to be a human being. See LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW, 893 (1978).

Under Article I, section 2 of the Florida Constitution, "[a]ll natural persons are equal before the law and have inalienable rights, among which are the right to enjoy and defend life and liberty No person shall be deprived of any right because of race, religion or physical handicap."²¹⁰

This section particularly specifies that the physically handicapped should not be deprived of any rights. Furthermore, the right to life is specifically stated. Article I, section 2 appears to be especially pertinent to a child such as Baby Theresa who has suffered physical damage, and may lose her life consequent to that handicap. Furthermore, Article I, section 12 of the Florida Constitution provides "[t]he right of the people to be secure in their persons, houses, papers and effects against unreasonable searches and seizures . . . shall not be violated"²¹¹

Again, the seizure of a newborn infant's vital organs seems to fall within this section as a violation of the right of Baby Theresa to maintain her bodily integrity during her short life span. Article I, section 12 mandates that these organs not be removed. Finally, Article I, section 23 provides that "[e]very natural person has the right to be let alone and free from governmental intrusion into his private life except as otherwise provided herein."²¹²

The United States Constitution, Article IV, section 2[1] provides that "[t]he Citizens of each State shall be entitled to all Privileges and Immunities of Citizens in the several States."²¹³ State citizenship thereby grants each citizen the right to non-discriminatory treatment within each state of the fundamental rights of citizens of all the states. Furthermore, each state has the legislative authority over the rights to be granted to its citizens as long as the rights granted to its citizens are the same as the rights of the citizens of other states. Amendment IV of the United States Constitution provides that "[t]he right of the people to be secure in their persons . . . shall not be violated."²¹⁴ The protection against the forcible intrusion into the body of any person, including an anencephalic infant, is provided by the prohibition in the Fourth Amendment against unreasonable searches and seizures. "Consequently, even when competing interests dictate that an intrusion be required, only minor intrusions are permissible."²¹⁵ The Fifth

210. FLA. CONST. art. I, § 2.

211. FLA. CONST. art. I, § 12.

212. FLA. CONST. art. I, § 23.

213. U.S. CONST. art. IV, § 2, cl. 1.

214. U.S. CONST. amend. IV.

215. Friedman, *supra* note 14, at 939.

Amendment to the United States Constitution provides that "[n]o persons shall . . . be deprived of life . . . without due process of law."²¹⁶ Finally, the Fourteenth Amendment states that:

All persons born or naturalized in the United States and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any persons of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.²¹⁷

Certainly Baby Theresa was born in the United States and by definition, if she is a person, she is a citizen of the United States and the State of Florida.

While no other state abridges an anencephalic infant's privilege to die an unassisted death nor interferes with that child's immunity against an assisted death or infanticide, the Fourteenth Amendment itself "prohibits any State from abridging the privileges or immunities of citizens of the United States, whether its own citizens or any others."²¹⁸ The Fourteenth Amendment does not merely require equality of privileges, but it also demands that the privileges or immunities of all citizens shall be absolutely unimpaired.²¹⁹

The Fourteenth Amendment was drafted in order "to place limits on state action adverse to individuals."²²⁰ The Fifth Amendment was drafted to limit "federal deprivations of personal interests without due process of law."²²¹ "Where certain fundamental rights are involved, the Court has held that regulation limiting these rights may be justified only by a compelling state interest."²²² The due process requirement was a decision by lawmakers to safeguard fundamental rights and values vital in a free society which may be subject to denial by the majority. "Adequate protection of such 'core' concerns cannot be afforded by 'balancing' the

216. U.S. CONST. amend. V.

217. U.S. CONST. amend. XIV, § 1.

218. LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW, 415 (1978) (quoting from *Colgate v. Harvey*, 296 U.S. 404, 428 (1935)).

219. *Id.*

220. *Id.* at 535.

221. *Id.*

222. *Roe v. Wade*, 410 U.S. 113, 155 (1973); *Kramer v. Union Free School District*, 395 U.S. 621, 627 (1969); *Shapiro v. Thompson*, 394 U.S. 618, 634 (1969); *Sherbert v. Verner*, 374 U.S. 398, 406 (1963).

general interests of the majority against those of the individual."²²³

The threat of denial of the "life, liberty or property" interests trigger the procedural safeguards afforded by the due process clause. These protections were "designed to protect the fragile values of a vulnerable citizenry from the overbearing concern for efficiency and efficacy" ²²⁴ Any deprivation of "life, liberty or property by adjudication" must be subject to notice and a hearing, the right to present evidence, and the right to confront and cross examine adverse witnesses. ²²⁵ The right to representation by counsel is constitutionally required "where such assistance would be especially useful given the nature of the issues and the ability of the claimant to express himself adequately."²²⁶ The status of anencephaly does not deprive a citizen of the protections of the constitution.

An anencephalic live born human infant, under the jurisdiction of the state and federal constitutions, has the right to treatment as an equal. When dealing with anencephalic infants as a group, one must remember that an anencephalic infant falls into two semi-suspect classes: the condition of being handicapped and the condition of being a child. The right to life and the right to bodily integrity are recognized as constitutionally fundamental. "Children need not be recognized as a despised minority for all purposes in order to suspect the lawmaker whose only excuse for a deprivation that would be intolerable as to adults is that 'only children' are affected."²²⁷ Absent the fact of childhood, taking the life of an anencephalic infant constitutes an action which facially appears beyond the power of the state. ²²⁸ "[W]hatever may be their precise impact, neither the Fourteenth Amendment nor the Bill of Rights is for adults alone."²²⁹

The right of privacy under the United States Constitution is described in *Griswold v. Connecticut*²³⁰ as a peripheral right emanating from the penumbras of several fundamental constitutional guarantees "includ[ing] a parental right of discretion in raising . . . children and the right to exercise [a] child's privacy rights."²³¹ A presumption that the parent will act in the child's best interests underlies the exercise of these rights. In the case of

223. *TRIBE*, *supra* note 218, at 543.

224. *Id.* at 541 (quoting from *Stanley v. Illinois*, 405 U.S. 645, 656 (1972)).

225. *Id.* at 544-51.

226. *Id.* at 553.

227. *Id.*

228. *TRIBE*, *supra* note 218, at 1078.

229. *In re Gault*, 387 U.S. 1, 13 (1967).

230. *Griswold v. Connecticut*, 381 U.S. 479 (1965).

231. *Id.* at 494-95.

anencephalic organ sources, however, parent and child privacy rights come into conflict.²³² When the parents' decision to allow harvestation of their anencephalic child's organs while the child respire and has blood which circulates without assistance, the child's natural right to life will cause the state to abridge the presumption of parental autonomy.²³³ The privacy right is the right of the child which may, under limited conditions, be exercised by the parents.²³⁴ However, when the parents' and the child's rights conflict, the parents should not be able to exercise the child's rights.

The Florida courts have decided cases in which the child's privacy rights were exercised by the parents. In *In re Guardianship of Barry*,²³⁵ the parents of a ten month old child who was in a chronic vegetative coma, absent brain function and terminally ill, successfully petitioned to terminate the use of the life support which kept their child alive.²³⁶ A California court following the *Barry* court's reasoning indicated that the rights of parents are not absolute and that the state may interfere with the parent and child relationship in order to protect the child's well-being.²³⁷ "One of the most basic values protected by the state is the sanctity of human life."²³⁸ The Florida Supreme Court, quoting the Second District Court of Appeal's opinion in *In re Guardianship of Browning*,²³⁹ held:

One does not exercise another's right of self-determination or fulfill that person's right of privacy by making a decision which the state, the family, or public opinion would prefer The Ethics and Advocacy Task Force, as amicus curiae, raises a very legitimate concern that the "right to die" could become a license to kill. There are times when some people believe that another would be "better off dead" Euthanasia is a crime in this state.²⁴⁰

In many ways, the United States Supreme Court's decision in *Roe v. Wade*²⁴¹ changed the manner in which the American public values human life. Some of these, perhaps prophetic, moral concerns, expressed both

232. Paliokas, *supra* note 14, at 226.

233. *Id.* at 229.

234. *Id.*

235. *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. 2d Dist. Ct. App. 1984).

236. *Id.*

237. *In re Phillip B.*, 92 Cal. App. 3d 796 (1979), *cert. denied*, 445 U.S. 949 (1980).

238. *Id.*

239. *In re Guardianship of Browning*, 568 So. 2d 4 (Fla. 1990).

240. *Id.* at 13.

241. *Roe v. Wade*, 410 U.S. 113 (1973).

before and after the Court's decision, are: 1) the danger to other unborn humans, should abortion spread and perhaps become obligatory in certain cases, and the danger to newborns, the retarded, and the senile should society begin to take the lives of those considered expendable; and 2) the danger that physicians and nurses and those associated with the act of abortion might lose their traditional protective attitude toward life if they become inured to taking human lives at the request of the mothers.²⁴² These moral concerns are partially incorporated in the "slippery slope" or "wedge" objection. Theorists argue that the second step of the slippery slope or "wedge" which succeeds *Roe v. Wade* is the danger to handicapped newborns. The "wedge" objection, specific to the issue of anencephalic infants postulates that if termination of anencephalic infants is permitted as a general line of conduct, what will be the second or next step? Just as the "wedge" objection was raised in *Roe v. Wade* (if termination of the unborn is permitted, the second step may be termination of the newly born), the "wedge" objection cautions against the termination of other severely handicapped and decerebrate humans. To paraphrase the "wedge" objection: "whether or not the first step is precarious, is perilous, is worth taking, rests in part on what the second step is likely to be."²⁴³ Separating our government from the governments of other nations which have permitted the violations of human rights is the United States Constitution. The Supreme Court's opinions interpret the Constitution and "draw the line" between the lawful and the unlawful. The encroachments, however slight, on the safeguards of the Constitution and the Bill of Rights could damage the fabric of our lives and the character of our civilization.

Commentators who favor the legalization of harvesting anencephalic infants' organs argue that the particular characteristics of anencephaly would not be confused with any other category of handicapped or decerebrate human being and that no other handicapped person could be endangered. Furthermore, they assert that the "slippery slope" or "wedge" objection is needlessly pessimistic, even hyperbolic. However, the critics of harvesting anencephalic infants' organs point out that the proposed legal authority to take these organs could be the next successive step in the "wedge" initiated by *Roe v. Wade*.²⁴⁴ One generation ago, critics point out, abortion was an illegal act. In the past twenty-five years, abortion has been legal in some states, and then legalized, under certain conditions, by the United States

242. Sissela Bok, *Ethical Problems of Abortion*, REVISED BIOETHICS 45-46 (1981).

243. YALE KAMISAR, DEATH, DYING AND EUTHANASIA 467-78 (Dennis J. Horan & David Mall eds. 1980).

244. 410 U.S. 113 (1973).

Supreme Court. Since that time, tens of millions of fetuses have been destroyed. The harvesting of anencephalic infants' organs fulfills the prophecy of abortion opponents that terminating the recently born was to be the next step after the destroying the unborn. The "wedge" theory has been demonstrated historically in the United States and in Europe. In each case, rational arguments were made for the taking of the first step.

Even before the Nazis took open charge in Germany, a propaganda barrage was directed against the traditional compassionate nineteenth-century attitudes toward the chronically ill, and for the adoption of a utilitarian, Hegelian point of view . . . Lay opinion was not neglected in this campaign. Adults were propagandized by motion pictures, one of which, entitled "I Accuse," deals entirely with euthanasia. This film depicts the life history of a woman suffering from multiple sclerosis; in it her husband, a doctor, finally kills her to the accompaniment of soft piano music rendered by a sympathetic colleague in an adjoining room. Acceptance of this ideology was implanted even in the children. A widely used high-school mathematics text . . . included problems stated in distorted terms of the cost of caring for and rehabilitating the chronically sick and crippled. One of the problems asked, for instance, how many new housing units could be built and how many marriage-allowance loans could be given to newly wedded couples for the amount of money it cost the state to care for "the crippled, the criminal and the insane . . ." The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. *It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived.* This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitative sick.²⁴⁵

Additionally, in his dissenting opinion, in the case of *Korematsu v. United States*, Supreme Court Justice Jackson described the "wedge" principle as follows:²⁴⁶

245. KAMISAR, *supra* note 243, at 468-69 (emphasis added) (citation omitted).

246. *Korematsu v. United States*, 323 U.S. 214 (1944).

All who observe the work of the courts are familiar with what Judge Cardozo described as "the tendency of a principle to expand itself to the limit of its logic." . . . A military commander may overstep the bounds of constitutionality, and it is an incident. But if we review and approve, that passing incident becomes the doctrine of the Constitution. There it has a generative power of its own, and all that it creates will be in its own image.²⁴⁷

Finally, in the case of *Boyd v. United States*,²⁴⁸ the landmark search and seizure case which facilitated the federal rule of exclusion, the Supreme Court elucidated the "wedge" principle as follows:

It may be that it is the obnoxious thing in its mildest and least repulsive form; but illegitimate and unconstitutional practices get their first footing in that way, namely, by silent approaches and slight deviations from legal modes of procedure It is the duty of courts to be watchful for the constitutional rights of the citizen, and against any stealthy encroachments thereon. Their motto should be *obsta principiis*.²⁴⁹

The constitutions of the state and federal governments were drafted to protect the human rights of the citizenry who are identified as "persons" under the various constitutions. Should Baby Theresa, or anencephalic infants in general, be deemed non-persons, their rights under the constitutions would vanish. Whether or not the Baby Therasas of the United States receive the protections of the law depends upon the ultimate resolution of that question of personhood by the highest courts of the United States.

XI. BIOETHICAL CONCERNS IN ORGAN TRANSPLANTATION

Bioethics involves the "study of the ethical problems that arise from the interrelationship between medical or biological research and technological advances on one hand and the rights and future of humans on the other."²⁵⁰ Baby Theresa was an example of a current bioethical dilemma. The proposed selective euthanasia or infanticide of a newborn anencephalic child for the purpose of harvesting her organs is the product of advanced

247. KAMISAR, *supra* note 243, at 474 (citation omitted).

248. *Boyd v. United States*, 116 U.S. 616 (1886).

249. *Id.* at 635.

250. PETER A. ANGELES, *HARPER COLLINS DICTIONARY OF PHILOSOPHY* (2d ed. 1991).

medical research. Arguably, it infringed not only on the rights of Baby Theresa, but also on the future rights of other severely handicapped human beings.

If Dr. Shewmon is accurate (or nearly accurate) in his predictions of successful organ transplantation from the source pool of all anencephalic infants, arguably nine heart, two liver and zero kidneys could be beneficially utilized each year by other handicapped organ donees.²⁵¹ In the United States, the Project on Organ Transplantation estimated that there were currently 3,000 deceased human beings each year who could be made available as sources for transplantable organs under the guidelines of the Uniform Anatomical and Gift Acts.²⁵² About 10,000 people now await kidney transplants, with the number rising to 25,000 if suitable donors were available.²⁵³ Another 100 individuals currently await heart transplants, with that number rising to 14,000 if suitable donors were available.²⁵⁴ The drafters of the National Organ Transplant Act²⁵⁵ estimated that from 12,000 to 27,000 human beings die each year in the United States from "brain injury, brain tumor, stroke or other conditions that would permit cadaver organ recovery."²⁵⁶

Although surveys show that from forty percent to seventy percent of the population is willing to donate cadaver organs, only seventeen percent of the population have actually executed donor cards.²⁵⁷ Organ procurement in the United State is governed by the Uniform Anatomical Gift Act, adopted by all fifty states and the District of Columbia.²⁵⁸ This Act provides that organs can be procured if the donee has signed a donor card while alive, or if the prospective donee has not objected to organ donation during his lifetime, the next of kin may donate after the death of the individual.²⁵⁹ If cadaver organs were routinely salvaged, instead of donated, without the necessity of "donee" consent, many more organs would be available, more in keeping with the estimated 12,000 to 27,000

251. Shewmon, *supra* note 2, at 1774.

252. *Id.*

253. *Id.*

254. *Id.*

255. *Id.*

256. ROBERT M. VEATCH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION 211 (rev. ed. 1989).

257. *Id.* at 212-13.

258. Unif. Anatomical Gift Act of 1968, 8A U.L.A. 15 (1983 & Supp. 1989); see Botkin *supra* note 97, at 252.

259. Unif. Anatomical Gift Act of 1968, 8A U.L.A. 15 (1983 & Supp. 1989).

predictable from cadaver organ recovery or salvage plan.²⁶⁰ Under the Uniform Anatomical Gift Act, only a rare death provides organs needed for transplant. However, the objection to the routine salvaging of decedents' organs was both moral and legal, and was instrumental in the "gift" mandate of the Act.

Do we want to be a society that conceives of body parts as essentially property of the state to be taken by eminent domain? . . . If the state can assume that human bodies are its for the taking . . . what will be the implication for the less ultimate, less sacred possessions?²⁶¹

Lawmakers have respected the religious views of Orthodox Jews and Jehovah's Witnesses which strictly forbid removal of body organs after death, and have drafted the Uniform Anatomical Gift Act consistent with the interests in cultural and common law views concerning the duties and obligations towards dead bodies. Thus, the salvaging of cadaver organs from the 12,000 to 27,000 usable bodies (hypothetically available each year) has been effectively precluded by existing laws, drafted partially, at least, in respect for religious, ethical and cultural values of the population.

Dr. Willard Gaylin, the President of the Institute of Society, Ethics and the Life Sciences, predicted a future in which "brain dead bodies, maintained on artificial life supports and collected in large bioemporiums would replace embalmed cadavers for the purpose of medical research, therapy or education."²⁶² Should a patient be declared brain dead, it is possible under the present legal structure to artificially maintain the body (if proper legal consents have been obtained) so that it is "clinically possible to maintain respiration and other vital functions in a brain dead body for weeks or months."²⁶³ Consequently, fresh organs from biomorts have, to a great extent, replaced cadaver organs for transplant purposes. "[M]edical specialists estimate that brain deaths produce 20,000 suitable organ donors each year in the United States."²⁶⁴ Dr. Gaylin more generously estimated

260. VEATCH, *supra* note 256, at 211-13. Under the salvage plan, prospective organ sources could sign a card indicating that they did not want their organs salvaged after their death, and thus, they would remain protected from having their organs removed.

261. *Id.* at 213.

262. Susan R. Martyn, *Using the Brain Dead for Medical Research*, 1 UTAH L. REV. 1, 1-2 (1986).

263. *Id.* at 3.

264. *Id.* at 5.

that brain deaths due to accident, homicide, suicide, stroke and heart attack could produce 70,000 biomorts each year.²⁶⁵

Biomort organs and tissue already benefit the living, as biomorts are commonly used as organ donors.²⁶⁶ Surgeons have progressed from simple kidney transplants to more complicated transplants of other vital organs, such as the heart and the liver. Studies of the immune system are now paving the way for transplantation of all organs, glands and other miscellaneous body parts. Even the brain, or parts of it, may one day be replaceable. Proposals have also been made for harvesting tissue and fluids. Entire blood banks could be replenished with biomort blood. Other substances, such as the pituitary growth hormone, or insulin, could also be collected easily.

In sum, adequate supplies of biomorts would obviate the need for many of the human and animal guinea pigs currently used to further medical and scientific research. Biomorts can also be used to teach medical and surgical techniques. Most importantly, biomorts' parts or products can directly assist the living.²⁶⁷ In order to control and safeguard against the abuse of biomorts and to encourage public confidence in organ and body donation, safeguards must be provided. Whole brain death must be assured with absolute certainty; need and therapeutic benefit should be weighed against respect for the dead, and adequate disclosure must be provided to all potential donors.

The Loma Linda protocol was based upon the maintenance of artificial life support for the twelve anencephalic infants who comprised the program. Life support and intensive medical care for each of these infants was limited to seven days in order to preclude the indefinite extension of the death process and to avoid charges of organ farming or using the anencephalic infants as biomorts.²⁶⁸ The California Medical Association, the United Network for Organ Sharing and the California Nurses Association opposed the use of live born anencephalic infants as organ sources, and the application of special treatment to the babies in order to obtain their organs.²⁶⁹

265. *Id.*; see also Gaylin, *Harvesting the Dead*, HARPERS BAZAAR 23-30 (Sept. 1974).

266. Martyn, *supra* note 262, at 6 & n.27.

267. *Id.* at 8.

268. See *supra* notes 115-124 and accompanying text.

269. Each of these organizations have prepared position papers on this topic.

The California Nurses Association also raised the question of distributive justice, questioning expensive procedures which benefit few individuals.²⁷⁰ Specifically, the cost of organ transplantation is very high.²⁷¹ A kidney transplant averages \$32,190, a heart transplant costs approximately \$125,000, and a liver transplant is \$267,000.²⁷² Immunosuppression drugs cost from \$10,000 to \$20,000 per year, and a patient will need these drugs for the rest of his life.²⁷³ Finally, there are other costs associated with the transplant, and of course, these costs are additional.²⁷⁴

The bioethics of our society is and will continue to be under siege. Today's technological and medical advances invite tomorrow's utilitarian decisions. In a society which values physical perfection, as well as power, and which devalues the imperfect, the weak and the poor, people constantly ask themselves bioethical questions. The answer to the anencephalic question may be a litmus test for a future in which other bioethical problems are bound to arise. The bioethical issues looming on the horizon include: the use of fetal tissue from intentionally aborted fetuses for research purposes; the neonatal care to be afforded to "drug babies" born early, weak and handicapped, who now overpopulate intensive care nurseries; the suicide books suggesting to the aged or the chronically ill that they should consider the financial and emotional expenditure they may save their families by avoiding a long, lingering death; and the proponents of active euthanasia who seek to terminate the lives of those whose existences appear to be burdensome.

Not many organs could be successfully harvested from anencephalic neonates. However, sufficient organs may be available for transplant if the Uniform Determination of Death Act is re-drafted to provide for organ salvage—another bioethical dilemma. Finally, should medical resources be distributed in such a way that an anencephalic infant, whose mother most likely had little or inadequate prenatal care, be harvested for the use by another handicapped infant whose parents (or their insurance) can afford the hundreds of thousands of dollars needed to effectuate and sustain that transplant? The future bioethical decisions are to be made by a culture

270. California Nurses Ass'n Ethics Committee, *California Nurses Association Position Statement on Anencephalic Infants as Organ Donors* (1988).

271. Alexander M. Capron & Fred H. Cate, *Death and Organ Transplantation*, 21 *TREATISE ON HEALTH CARE* 21-1 (1991).

272. *Id.*

273. *Id.*

274. *Id.* at 21-88.

which values money, possessions and power. Fortunately, the people of that culture are individually protected by the Constitution.

XII. CONCLUSION

Baby Theresa is not just a symbol for all the live born anencephalic infants who may have organs useful to other handicapped infants; she is a symbol of the weakest class of human beings who may be declared non-persons because they lack certain cognitive abilities. If anencephalic infants can be the sources of approximately eleven successful organ transplants per year, as predicted by Dr. Shewmon, the "non-person" source pool may necessarily have to be expanded to include other defective newborns and other gravely disabled human beings. Perhaps abnormal and normal neonates and other young infants may be determined to have minimal cognitive ability, and thus, be subject to termination under guidelines similar to the guidelines proposed to end Baby Theresa's life. In considering the bioethical questions regarding the future of anencephalic infants, various questions may come to mind. Practically, should the weak, the poor and the handicapped be sacrificed for their utility to the stronger, the wealthier and the less handicapped? Philosophically, should the technological advancement of organ transplantation be encouraged with the vivisection of anencephalic infants? And sociologically, is organ harvesting from human infants with autonomous cardiopulmonary activity scientific progress or is it an atavistic reversion to remote ancestral practices?

A more efficacious way of delivering organs to needy transplant patients would be to revisit the Uniform Anatomical Gift Act in order to access the 12,000 to 27,000 human beings who die each year from brain tumor, stroke and other conditions, and whose intubated bodies may be available for cadaver organ recovery. But, to revise the brain death law or the cardiopulmonary common law definition of death or to revise the definition of a "person" as protected under the Federal and state constitutions to exclude the weakest members of society could irrevocably damage the fabric of our lives, the protections of our laws and the character of our civilization.²⁷⁵

275. On November 12, 1992, the Florida Supreme Court handed down its opinion in this case. *In re T.A.P.C.*, 17 Fla. L. Weekly S691 (Fla. Nov. 12, 1992).