

# LIFE, DEATH AND THE LAW: SHOULD THE ANENCEPHALIC NEWBORN BE CONSIDERED A SOURCE FOR ORGAN DONATION?

## TABLE OF CONTENTS

INTRODUCTION .....	299
I. LIFE AND DEATH: ANENCEPHALY AND THE LAW.....	302
A. <i>The Nature of Anencephaly</i> .....	302
B. <i>The Anencephalic Infant as Organ Donor</i> .....	303
C. <i>The Anencephalic Infant and The Legal Standard of "Life"</i> .....	306
II. LEGAL RIGHTS AND PROTECTIONS .....	310
A. <i>Personhood and Inalienable Rights</i> .....	311
B. <i>Personhood and Legal Rights</i> .....	312
1. <i>The Right to Bodily Integrity</i> .....	314
2. <i>Substituted Judgment and Best Interests</i> ....	316
C. <i>Public Policy Interests in Protecting the Infant with Anencephaly</i> .....	318
III. PARENTAL RIGHTS AND THE ANENCEPHALIC NEWBORN.....	320
A. <i>Parental Rights and Decision-making</i> .....	320
B. <i>Checks and Balances: The Role of Physicians and the Courts</i> .....	325
VI. THE CALL FOR COMPROMISE: IS THERE A LEGITIMATE BASIS FOR A BALANCING APPROACH?.....	327
EPILOGUE .....	330

### INTRODUCTION

On March 21, 1992, Theresa Ann Campo-Pearson became the center of a national debate. The hours-old infant was born in a Florida hospital with a terrible birth defect known as anencephaly—a large opening in the skull accompanied by the complete or near total absence of normal cerebral hemispheres.<sup>1</sup> In lay-

---

1. David A. Stumpf et al., *The Infant with Anencephaly*, 322 NEW ENG. J. MED. 669, 670 (1990).

man's terms, she was born without a brain. While "Baby Theresa" lived for only nine days, what distinguished her life from others born like her was the legal battle waged by her parents, Laura Campo and Justin Pearson. After the hospital refused their request to declare their child dead so that her tiny organs could be harvested and donated to other children, they took their case to the Florida Supreme Court in an effort to change the definition of death so that others might have the option they were denied. Their heartrending story was covered nationally over the nine short days of the infant's life, with pictures of tiny Theresa Ann, cradled in her mother's arms or clutching her grandmother's fingers, exhibited against a narration of the legal issues involved. Reporters watching as the pair came before Broward County Circuit Judge Estella M. Moriarity, described a tragic scene where even the judge fought back tears.<sup>2</sup> There seemed to be no easy answers.

Seven months later, in a landmark ruling, the Florida Supreme Court gave its answer, ruling unanimously against the parents and holding that the current definition of death should not be changed simply to allow more organs to be donated for transplants.<sup>3</sup> The court primarily rested its decision on the applicable Florida statutes<sup>4</sup> and the common law definition of death,<sup>5</sup> but it also explored whether a public necessity existed that would justify making an exception for Baby Theresa. In declining to do so, the court decided there was no apparent consensus among medical, ethical, or legal authorities on anencephaly.<sup>6</sup> It did acknowledge the possibility that some infants' lives might be saved by using organs from anencephalics who did not meet the traditional definition of "death," but when weighed against the utter lack of consensus and questions about the overall utility of such organ donations, this possibility was not enough to "tip the scales" in favor of extending the common law *in this instance*.<sup>7</sup> The door was, however, left open for legislative action. Thus, although it represented the first actual decision of its kind, *In re T.A.C.P.* was hardly dispositive.

---

2. Carole Ashkinaze, *Theresa's Parents Tried to Honor Life*, CHI. SUN-TIMES, Mar. 31, 1992, at 25.

3. *In re T.A.C.P.*, 609 So. 2d 588, 595 (Fla. 1992).

4. *Id.* at 592.

5. *Id.* at 591.

6. *Id.* at 594.

7. *Id.* at 595.

In its wake, the argument for a statutory change in the definition of death that would exclude anencephalics has been raised again in both the medical and legal communities,<sup>8</sup> and a nine-member American Medical Association Council on Ethical and Judicial Affairs has recommended that infants born with anencephaly should be considered necessary sources for organs needed for transplant.<sup>9</sup> To legislate such a change would raise a host of legal and ethical issues going well beyond the economics of organ supply and demand. As this Comment will argue, such a statute falls completely outside our legal history and tradition, and is totally inconsistent with the current law protecting individual autonomy and the right to bodily integrity. Furthermore, there are serious ethical questions concerning how far such a policy might go.

Section II of this Comment will review the relevant medical and statutory history behind the case of Baby Theresa, discussing the nature of anencephaly, the current statutory definitions of life and death, and explain why, within this framework, the infant with anencephaly is in fact, alive. Section II will also examine the rationale behind the various proposals to use anencephalic infants as a source of donor organs. Section III addresses the major legal issues bearing on the problem, focusing on the legal rights of the anencephalic newborn, and relevant public policies that are implicated. Section IV will explore the legal rights and interests of the parents.

Section V, in conclusion, asks, "Is there a legitimate basis for a balancing approach?" and debates the difficult question of whether one life has so little value that the interests inherent in that life can morally and ethically be sublimated for the preservation of another. Put more directly, when two children are born with fatal defects, one with anencephaly and the other with a different congenital abnormality that may be correctable through transplantation, should the anencephalic be considered a

---

8. See, e.g., Jay A. Friedman, *Taking the Camel by the Nose: The Anencephalic as a Source for Pediatric Organ Transplants*, 90 COLUM. L. REV. 917 (1990) (advocating a change in the law); David T. McDowell, *Death of an Idea: The Anencephalic as an Organ Donor*, 72 TEX. L. REV. 893 (1994) (Friedman's proposal is precluded in the wake of the decision in *In re T.A.C.P.*); Andrea K. Scott, *Death Unto Life: Anencephalic Infants as Organ Donors*, 74 VA. L. REV. 1527 (1988) (arguing for the necessity of a uniform policy); Robert D. Truog & John C. Fletcher, *Anencephalic Newborns: Can Organs be Transplanted Before Brain Death?*, 321 NEW ENG. J. MED. 388 (1989) (proposal for statutory change); Donald N. Medearis & Lewis B. Holmes, *On the Use of Anencephalic Infants as Organ Donors*, 321 NEW ENG. J. MED. 391 (1989) (arguing against such use).

9. 37 AM. MED. NEWS, No. 24, Oct. 17, 1991, at 14.

“source” in order that the other might live? The answer is a resounding, “No.” As this Comment will argue, all persons are born with certain inalienable rights and a set of legal protections that accompany them. To deny those protections to even the least among us would compromise the moral basis of our system for a utilitarian purpose. Even with the purest motives and the best of intentions, we cannot allow that to happen.

## I. LIFE AND DEATH: ANENCEPHALY AND THE LAW

### A. *The Nature of Anencephaly*

*The first sign of trouble came on a Thursday in February. Campo, 30 weeks pregnant, was flat on her back at the Broward Family Health Clinic in Fort Lauderdale, where she was enrolled in a prenatal program for indigent mothers. On the little television screen above her bed floated the image of her baby. As the technician ran his finger across the screen, he pointed out the liver. The heart. The stomach. The hands. The feet. The spine. The neck. And then he stopped.*

*A week later, she came back for another test. The image was a cipher and her doctor would have to explain. “Something’s not right here,” he told her. “What’s the matter?” she asked. All he could say was, “It’s the head. The top of the head.” “The top of the head?” she wondered, “what on earth could that mean?”*

*Doctors performed another ultrasound a couple of days later. This time, the baby’s head didn’t show up on the screen. And then, Campo learned the truth: The head didn’t show up because there was no skull — or brain — for the sound waves to bounce off of. The head was hollow.<sup>10</sup>*

The diagnosis, anencephaly, meant that the infant would be born with a rare, congenital disorder in which a major portion of the brain, skull and scalp are missing.<sup>11</sup> Anencephaly is not only severely disabling, it is invariably fatal.<sup>12</sup> The lack of a cerebral cortex renders the infant permanently unconscious and

---

10. *Life, Death and Baby Theresa; A Baby Born without a Brain Clings to Life as Her Parents Seek a Ruling that would Allow Her to Die in Order to Save Others*, ORLANDO SENTINEL TRIB., Mar. 30, 1992, at A1.

11. Stumpf, *supra* note 1, at 669.

12. *Id.* at 672.

it is only due to the presence of a functioning brain stem that the heart and lungs operate to keep the infant alive.<sup>13</sup> Medical research is inconclusive, but it is believed that such infants are incapable of any sensory perception at a conscious level, although they do respond reflexively to noxious stimuli and exhibit feeding reflexes, respiratory reflexes, and many interactions involving eye movements and facial expressions that are seen in newborns with intact cerebral hemispheres.<sup>14</sup>

The incidence of anencephaly in the United States is extremely low — estimated at approximately .3 per 1000 births, or 1050 per year,<sup>15</sup> approximately two-thirds of whom are stillborn.<sup>16</sup> In those cases where anencephalics do survive, they rarely live more than twenty-four hours, and only one out of seven are alive at the end of seventy-two.<sup>17</sup> Baby Theresa herself was a remarkable case. She lived for nine days while her parents fought their desperate battle in the courts.

### B. *The Anencephalic Infant as Organ Donor*

*The night of the ultrasound test, Campo phoned her friend, Ginnie Abraham. They had a long talk. Campo recalled a television show, something about babies with no brains, something about donating organs. Campo repeated her conversation to Pearson. Maybe something good could come from their heart-ache. Maybe, if they donated Theresa's organs to other children, she would live on, through them.*<sup>18</sup>

In recent years, pediatric organ transplantation has become an increasingly viable option for giving critically ill children the opportunity for a healthy life.<sup>19</sup> However, as with adult transplantation, the supply of usable organs has not kept up with the ever increasing demand.<sup>20</sup> Among children younger than two years of age registered to receive transplants, an estimated 30-

13. *Id.*

14. *Id.*

15. *Id.* at 671.

16. P.A. Baird & A.D. Sadovnick, *Survival in Infants with Anencephaly*, 23 CLINICAL PEDIATRICS 268, 268 (1984).

17. *Id.* at 269.

18. ORLANDO SENTINEL TRIB., *supra* note 10.

19. AM. ACAD. OF PEDIATRICS; COMM. ON BIOETHICS, *Infants with Anencephaly as Organ Sources: Ethical Considerations*, 89 PEDIATRICS 1116, 1116 (1992) [hereinafter COMM. ON BIOETHICS].

20. *Id.*

50 percent die before organs become available.<sup>21</sup> As scientific technology improves, these numbers will only increase, and in legislatures and hospitals around the country, the search is on for new sources of viable organs. In light of the universally fatal nature of anencephaly, and the fact that apart from their neurological malformation, their organs are presumed suitable for transplantation, it is not surprising that many are looking to anencephalics as one way to alleviate this shortage.<sup>22</sup> However, a number of factors combine to make this an impractical solution.

The main problem is that since most anencephalic infants die from cardiorespiratory failure, by the time they are declared dead, their organs have become medically unsuitable for transplantation due to inadequate perfusion.<sup>23</sup> Customary medical care includes warmth and feeding with no major medical interventions, but if their organs are to be harvested while still usable, a change in the standard of treatment is necessary.<sup>24</sup>

Four approaches have been proposed for obtaining organs from anencephalic infants. One, investigated in Canada and tried in at least one U.S. institution,<sup>25</sup> entails resuscitation at birth and maintenance of intensive care to protect organ viability until total brain death occurs.<sup>26</sup> A predetermined period of seven to fourteen days for maintenance is included in this approach.<sup>27</sup> However, in a study where infants were monitored for seven days, only one of six lost all brain function.<sup>28</sup> Furthermore, despite the medical evidence that indicates these infants cannot consciously experience pain, doubts remain and ethical questions about the humanity of such treatment still exist.<sup>29</sup>

A second approach is a less assertive variation of the first, where customary medical care is administered to the infant until

---

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

22. Aubrey Milunsky, *Harvesting Organs for Transplantation from Dying Anencephalic Infants*, 82 PEDIATRICS 274 (1988).

23. Perfusion is defined as, "the flow of blood or other [fluid] per unit volume of tissue." STEDMAN'S MEDICAL DICTIONARY 1325 (26th ed. 1995).

24. COMM. ON BIOETHICS, *supra* note 19, at 1116.

25. Peabody, *supra* note 21, at 344. (This was the "Loma Linda Protocol," an experimental organ transplant program that was conducted in 1987 to facilitate organ donation from infants with anencephaly. It was abandoned after trials with 12 infants resulted in no transplants, and a storm of controversy ensued over the ethics of the treatment itself.)

26. COMM. ON BIOETHICS, *supra* note 19, at 1116.

27. *Id.*

28. *Id.*

29. Friedman, *supra* note 8, at 978 n.78.

signs of impending cardiorespiratory death develop. At that point, the child is given maximum life support and monitored for loss of brain function. If brain stem activity appears absent, the infant is evaluated as a potential organ source.<sup>30</sup>

A third method involves gradually cooling the anencephalic newborn's body to protect the organs from ischemia.<sup>31</sup> This effort to preserve the organs could also hasten death and may be viewed by some as a form of killing. This type of approach is sometimes justified as falling under the "doctrine of double effect," a term applied to medical procedures that can have simultaneous good and bad effects. Such procedures are generally acceptable, but only when they are performed with the intent of promoting the good effect, and there is a compelling reason to allow the bad. The anencephalic's case presents a troubling departure from the usual application of this doctrine, since the normal principle governing treatment is that it is the patient's best interests that are of primary importance. Following the cooling approach, however, the benefit, or "good effect" is conferred upon potential donor recipients, not the anencephalic patient. Despite this concern, there is evidence that practices similar to this one have been followed in organ procurement from consenting adult donors once the determination has been made that the condition is inevitably fatal.<sup>32</sup>

While these three approaches are arguably within the bounds of current law regarding the definition of death, available evidence suggests that their utility in producing viable organs for transplant is negligible, as they are generally unsuccessful.<sup>33</sup> Furthermore, all require that a determination of brain death be made in very young infants.<sup>34</sup> This determination is complicated by guidelines adopted by the Special Task Force on the Determination of Brain Death in Children which recommended that the application of this criteria be limited to children 7 days or older.<sup>35</sup> The Task Force found that the normal criteria may not be valid in younger infants because important developmental processes may still be occurring.<sup>36</sup> Anencephalic infants present

---

30. COMM. ON BIOETHICS, *supra* note 19, at 1116.

31. Ischemia is defined as, "local anemia due to mechanical obstruction (mainly arterial narrowing) of the blood supply." STEDMAN'S, *supra* note 23, at 894.

32. COMM. ON BIOETHICS, *supra* note 19, at 1116-17.

33. Medearis & Holmes, *supra* note 8, at 391-92.

34. COMM. ON BIOETHICS, *supra* note 19, at 1117.

35. *Guidelines for the Determination of Brain Death in Children*, 80 PEDIATRICS 298, 298 (1987) (as quoted in COMM. ON BIOETHICS, *supra* note 19, at 1117).

36. *Id.*

an additional problem due to their lack of a functioning cerebral cortex, and assessment of cortical death in these infants may be impossible using neurological criteria alone.<sup>37</sup>

These considerations have given rise to the fourth, and most controversial approach—removing organs from anencephalic infants without waiting for a determination of either cardiorespiratory or brain death on grounds that these infants are “brain absent” and may be treated as if they were brain dead, or, alternatively, that they are sufficiently lacking in cognitive capacity that the usual moral constraints on killing persons do not apply.<sup>38</sup> This fourth approach is the one advocated by the parents of Baby Theresa. Adopting this approach would require a change in the legal definition of death, or the creation of a special legal exception for anencephalic infants that would allow physicians to remove vital organs before total brain death has occurred.<sup>39</sup> The effect would be to authorize actively causing death.<sup>40</sup>

One final consideration is that the birth rate of anencephalic infants is not only extremely low,<sup>41</sup> but it has the potential to be reduced even further by improved access to prenatal screening and diagnosis, causing many women to choose abortion rather than carry the child to term knowing that it will be either stillborn or die shortly anyway. In recent studies, the percentage of couples choosing abortion varied between 78 and 90 percent.<sup>42</sup> Factoring in this variable lowers the estimates on live births among anencephalic infants to as few as 34 per year.<sup>43</sup>

### C. *The Anencephalic Infant and the Legal Standard of “Life”*

*The diagnosis came too late for an abortion or induced labor. Upon hearing the news, Campo was informed she would have to carry the fetus full-term. That night, she and Pearson huddled together at home. Although their lives hadn't been easy, they had never before encountered anything like this.*

---

37. COMM. ON BIOETHICS, *supra* note 19, at 1117 (quoting Stumpf, *supra* note 1, at 672).

38. *Id.*

39. *In re T.A.C.P.*, 609 So. 2d 588, 591 (Fla. 1992).

40. COMM. ON BIOETHICS, *supra* note 19, at 1117.

41. *See supra* part II.A.

42. Stumpf, *supra* note 1, at 671.

43. Medearis & Holmes, *supra* note 8, at 391.



*Eventually, they decided that Campo would have a Cesarean. Not because it would be best for her, but because that way, the baby would have a chance of being born with its organs intact. The doctors would do what they could.*

*On the day of delivery, the doctors reached in to deliver Theresa Ann and the impossible happened. "When we pulled her out, the baby gave a spontaneous scream," said Dr. Wayne Di-Giacomo, one of Campo's obstetricians, "and she started breathing on her own."*

*Theresa-Ann's heart kept beating, and the law took over.<sup>44</sup>*

When those trained in medicine, philosophy, and theology are unable to arrive at any consensus [as to the difficult question of when life begins], the judiciary, at this point in the development of man's knowledge, is not in a position to speculate as to the answer. It should be sufficient to note the wide divergence of thinking on this most sensitive and difficult question. . . . Physicians . . . have tended to focus either upon conception, upon live birth, or upon the interim point at which the fetus becomes "viable," that is, potentially able to live outside the mother's womb, albeit with artificial aid.<sup>45</sup>

The definition of "live birth" is fairly settled. In general, state statutes are similar to that relied upon by the Florida Supreme Court in Baby Theresa's case, which defines "live birth" as:

The complete expulsion or extraction of a product of human conception from its mother, irrespective of the duration of pregnancy, which, after such expulsion, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, and definite movement of the voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached.<sup>46</sup>

"Fetal death" is defined as:

Death prior to the complete expulsion or extraction of a product of human conception from its mother if the 20th week of gestation has been reached and the death is indicated by the fact that after such expulsion or extraction the fetus does not breathe or show any other evidence of life such as beating

---

44. ORLANDO SENTINEL TRIB., *supra* note 10.

45. *Roe v. Wade*, 410 U.S. 113, 159-60 (1973) (footnotes omitted).

46. FLA. STAT. § 382.002(10) (1991).

of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.<sup>47</sup>

By analogy, the law of homicide requires that the victim be a living human being.<sup>48</sup> As applied to a fetus, once it is "fully brought forth" from the body of its mother, it is considered a human being.<sup>49</sup> Tort law is similar. In cases alleging wrongful death, courts have held that fetuses are not "persons" and are not born alive until they acquire an existence separate and independent from the mother.<sup>50</sup> It is clear that legally, Theresa Ann and other anencephalic infants who like her, demonstrate clear signs of independent vitality, are live human beings at birth, "entitled to the fullest protection of the law."<sup>51</sup>

Since the 1960's, as medical technology became capable of artificially supporting the biological functions of comatose patients for long periods of time, the lines between life and death began to blur. At common law, a human being was not considered dead until breathing and heartbeat had stopped entirely, without possibility of resuscitation,<sup>52</sup> but increasingly, the definitional criteria for death began to focus on the brain.

In 1968, a controversial report issued by the Harvard Medical School provided a four-part test for determining when brain death has occurred. The test, referred to as the "Harvard Criteria,"<sup>53</sup> led to the adoption, between 1970 and 1978, of legislation in nineteen states recognizing the concept of brain death.<sup>54</sup> In 1979, the Uniform Brain Death Act was approved by the National Conference of Commissioners on Uniform State Laws, expressing "community approval of withdrawing artificial life support systems when the whole brain has irreversibly ceased to work."<sup>55</sup>

---

47. FLA. STAT. § 382.002(7) (1991).

48. *Shedd v. State*, 173 S.E. 847, 847 (Ga. 1934).

49. *Jackson v. Commonwealth*, 96 S.W.2d 1014, 1014 (Ky. Ct. App. 1936).

50. *In re T.A.C.P.*, 609 So. 2d 588, 593 (Fla. 1992).

51. *Maine Med. Ctr. v. Houle*, No. 74-145, slip op. at 4 (Me. Super. Ct., Feb. 14, 1974).

52. *In re T.A.C.P.*, 609 So. 2d at 591.

53. The Harvard Criteria defined "whole brain death" as occurring when four conditions were met over a period of twenty-four hours, and verified not less than twenty-four hours after the initial testing with no change in the results. The conditions evaluated were: (1) unresponsiveness and unresponsiveness to externally applied stimuli; (2) no movements or breathing for a period of at least one hour; (3) no reflexes; (4) flat electroencephalograms. *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 337-38 (1968).

54. UNIF. BRAIN DEATH ACT, 12 U.L.A. 18 (1978 & Supp. 1995).

55. *Id.*

The Act addresses only the concept of brain death, not the criteria used to reach the conclusion that it had occurred.<sup>56</sup> The Uniform Brain Death Act was superseded in 1980 by the Uniform Determination of Death Act (hereinafter UDDA),<sup>57</sup> and most jurisdictions that had adopted it subsequently amended their laws to embrace the new criteria.<sup>58</sup> The UDDA states: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem is dead. A determination of death must be made in accordance with accepted medical standards."<sup>59</sup> As of the writing of this Comment, 32 states have adopted major portions of this standard,<sup>60</sup> while others have developed variations of their own.<sup>61</sup>

The UDDA reflects a conscious decision by the commissioners to adopt a standard of "whole brain death" versus "neocortical death," which refers only to the destruction of the two cerebral hemispheres.<sup>62</sup> The more expansive neocortical definition would classify individuals as dead even if they were breathing on their own, provided they lacked all higher brain functions.<sup>63</sup> Thus, the anencephalic infant, breathing without the aid of any mechanical means, would satisfy the neocortical standard of death. As yet, no state has accepted this definition.<sup>64</sup>

Proponents in the fight to use anencephalics as organ donors argue that the law should be amended to either accept the neocortical standard of death, or to allow a special exemption for infants born with anencephaly. In California and New Jersey, the only two states where attempts at statutory modification have been made, the efforts triggered a firestorm of controversy.<sup>65</sup> Today, the debate still focuses on the distinction between a dying person and one who is dead, "[for] if a dying person is accorded

---

56. *Id.*

57. UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 443 (1980 & Supp. 1995).

58. The exception is Alabama, where the state codification of the Uniform Determination of Brain Death Act was retained in ALA. CODE § 22-31-1(b) (1975).

59. UNIF. DETERMINATION OF DEATH ACT, 12 U.L.A. 443 (1980 & Supp. 1995).

60. *Id.*

61. See e.g. ALASKA STAT. § 09.68.120 (1994); CONN. GEN. STAT. § 19a-504a (1986) (applicable only to removal of life support systems); HAW. REV. STAT. § 327C-1 (1993); KY. REV. STAT. ANN. § 446.400 (Michie Bobbs-Merrill 1994) (requiring two physicians when brain death criteria is used); LA. REV. STAT. ANN. § 9.111 (West 1994) (requiring "irreversible total cessation of brain function" with no mention of brain stem).

62. Friedman, *supra* note 8, at 929 & n.66.

63. *Id.*

64. *Id.*

65. *Id.* at 936.

rights then use of anencephalics as donors violates those rights."<sup>66</sup> As Alexander Capron, Professor of Law and Medicine at the University of Southern California, and noted ethicist, wrote in 1986, "Anencephalic infants may be dying, but they are still alive and breathing. Calling them 'dead' will not change physiologic reality. . . ."<sup>67</sup>

## II. LEGAL RIGHTS AND PROTECTIONS

*Theresa Ann slept all the time, like any new baby. She kept her 10 little fingers rolled into tight fists and occasionally moved. She cried, sucked and swallowed. She had an innocent dignity all her own, and her lungs seemed to manage without life support. But she looked without seeing, she touched without feeling, and there was nothing inside her head to record life. Yet, as with any newborn, she stirred the protective emotions of everyone who watched her die her slow, inexorable death.*

*For each of her nine days of life, her grieving parents and their lawyers fought to have Theresa declared dead so that her organs could be transplanted into as many as five other critically ill babies. Once hopeful, they had carried this child to term, only to endure the pain of watching her die. The only thing left was to try and make something good come of this tragedy. In their desperate search for answers, they made their way through the courts. Losing there, they vowed to continue on to the legislature, to push for a law that would have declared their daughter to be dead upon birth. In the end, as they held her and kissed her before she slipped away, Theresa's parents promised they would make her life count.<sup>68</sup> What they overlooked was that our present laws would say that in terms of her rights as an individual, it already does.*

The legal issues are, fortunately, clearer than our emotions. No matter what sentiments are stirred when looking at the situation from a bedside view, the principles governing it are well settled and reach into the heart of our constitutional ideals of personal autonomy, liberty and privacy. It has been said that utilization of anencephalics as donors would not be inconsistent

---

66. Meilaender, *Commentary: The Anencephalic Newborn as Organ Donor*, HASTINGS CTR. REP., MAR.-APR. 1986, at 23.

67. Alexander M. Capron, *Anencephalic Donors: Separate the Dead from the Dying*, HASTINGS CTR. REP., Mar.-Apr. 1986, at 21.

68. ORLANDO SENTINEL TRIB., *supra* note 10.

with developing legal doctrine,<sup>69</sup> but this is wrong. To create an exception that would take the anencephalic infant outside the umbrella of protections that currently exist would be to enact fundamental change in the way our society views the values inherent in life. It would be a purely utilitarian change that would deny personhood to one category of life to benefit another.

The common law has consistently held to a rule which provides that one human being is under no legal compulsion to give aid or take action to save another human being or to rescue. . . . For our law to compel [a person] to submit to an intrusion of his body, and particularly one that would lead to a premature death, would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits . . .<sup>70</sup>

#### A. *Personhood and Inalienable Rights*

A legal analysis of the rights of an anencephalic newborn must begin with a determination of its status. Those who argue for a change that would exempt the infant from the current definitions of death do so based upon the premise that a permanently unconscious person with no past and no future has forever lost those characteristics that make us most human—awareness of self, of environment, and outside stimuli such as pain.<sup>71</sup> These traits certainly have a bearing on the quality of life. However, they don't define it. No matter how short or limited an anencephalic infant's existence outside of the womb may be, if, as with "Baby Theresa," it is breathing and its heart is beating on its own; the child is alive. As Dr. Aubrey Milunsky, of the Center for Human Genetics at Boston University School of Medicine, argues:

Any pediatrician who has examined a live anencephalic newborn will attest to the presence of a heartbeat, respiration, and brainstem functions. Indeed, in consoling grief-stricken parents and encouraging them to hold their baby, pediatricians will invariably point to the usually normal other body parts, having first placed a bonnet on the child's head.<sup>72</sup>

---

69. Friedman, *supra* note 8.

70. McFall v. Shimp, 10 Pa. D. & C.3d 90 (Allegheny County Ct. 1978).

71. Elizabeth G. Patterson, *Human Rights and Human Life: An Uneven Fit*, 68 TUL. L. REV. 1527, 1541 (1994).

72. Milunsky, *supra* note 22, at 275.

To declare such an infant “dead” defies the logic of what our senses tell us to be the truth.

As a “live” human being, the anencephalic infant is immediately endowed with a basic set of natural rights—rights which form the very bastion of one person’s equality and freedom vis-à-vis another.<sup>73</sup> Natural rights, far from merely an historical inheritance, are those tools that secure an individual’s position amongst all others, regardless of one’s perceived relative worth to society. Chief among these are the rights to life, limb, and property—the rights to life and limb refer to a person’s physical or mental integrity; the right to property extends this immunity to things, or assets, and sometimes opportunities.<sup>74</sup>

While certain rights are considered “alienable”—those that the right-holder can waive or renounce—basic rights are not, for alienability would defeat their very purpose as protective rights.<sup>75</sup> It is this protective feature of inalienable rights that limits our freedom to make self-restrictive or self-harming choices.<sup>76</sup> Thus when Rousseau declared that the true objection to slavery is not that it makes men unhappy, for some men are not unhappy as slaves, he meant that the objection is rather that it is unworthy of human beings to create such forms of life. What he had in mind was not equality for equality’s sake, but maintaining the individual in the company of equals—requiring basic rights of life and limb, so as to ensure the equal freedom of each individual.<sup>77</sup>

Our nation was founded on this idea, “that all men are created equal, . . . endowed by their Creator with certain unalienable rights,”<sup>78</sup> It is within this framework that the live-born anencephalic infant possesses the rights to life and limb from the moment it breathes outside the womb. No one—not the family, or the state—can take those rights away.

### *B. Personhood and Legal Rights*

The judicial affirmation of this principle is found within modern case law, where United States Courts have repeatedly affirmed that the status of being “alive” carries with it a set of

---

73. SAMUEL STOLJAR, AN ANALYSIS OF RIGHTS 90 (1984).

74. *Id.* at 95.

75. *Id.* at 90-91.

76. *Id.* at 91.

77. *Id.* at 92.

78. THE DECLARATION OF INDEPENDENCE, para. 1 (U.S. 1776).

legal protections that have nothing to do with the relative capabilities or worth of the individual. The Supreme Court, recognizing the importance of the determination of personhood to identifying their scope, addressed the issue directly in *Roe v. Wade*,<sup>79</sup> when it was called upon to determine the rights of the unborn in the context of abortion. "The Constitution does not define 'person' in so many words," said Justice Blackmun at the outset of his opinion.

Section 1 of the 14th Amendment contains three references to 'person.' 'Person' is used in other places in the Constitution. But in nearly all these instances, the use of the word is such that it has application [only] postnatally...<sup>80</sup>

....

The law has been reluctant to endorse any theory that life, as we recognize it, begins before live birth or to accord legal rights to the unborn except in narrowly defined situations and except when the rights are contingent upon live birth.<sup>81</sup>

Nowhere in the opinion is the term, "live birth" qualified in any way. In fact, while many other aspects of the decision in *Roe* have engendered boundless controversy, the statement that the law recognizes birth as the threshold for full personhood has never been challenged. Clearly, the live-born anencephalic infant falls within this pronouncement.

The fundamental nature of personhood is so vital that even before birth, our system recognizes that potential life has interests which must be protected, and confers certain legal protections in response.<sup>82</sup> The Court in *Roe*, while passing on whether life begins at conception, acknowledged that at some point, the State has a compelling interest in the protection of the unborn, and established that point at viability.<sup>83</sup> At no time did the Court state or even imply that the interests of the fetus were contingent upon the health or wellness of the child. Rather they are vested upon birth; and while many legal rights do vary by status, age, and mental capacity, there is no lasting precedent for simply denying their existence.

---

79. 410 U.S. 113 (1973). Although this Comment borrows heavily from the rationale behind the abortion decisions, it is not, in any way, intended to be an "abortion" paper, and the author takes no view on the issue of legalized abortion.

80. *Id.* at 157.

81. *Id.* at 161.

82. *Id.* at 160-61.

83. *Id.* at 163.

Furthermore, *Roe* allowed that while fetal rights must be balanced against the greater rights of the mother, at the point of viability, the State interest in protecting those rights may prevail.<sup>84</sup> Some jurisdictions have even held that the not-yet-viable fetus has interests that can outweigh some of the mother's constitutional rights.<sup>85</sup> Medicaid statutes lend additional support to legal recognition of the personhood of the fetus, regardless of its health, for while abortion funding exceptions in most states can be made in the case of rape, incest, or to save the life of the mother, there is no provision for funding pregnancy terminations merely because prenatal testing ascertains that the fetus is defective.<sup>86</sup> If an unborn child is given this level of protection, how much greater then, should the protection be for the newborn anencephalic whose existence, unlike that of the fetus, is neither integrated with nor dependent upon that of the mother?

It is further argued that permanent unconsciousness, as in the case of a patient who has become irreversibly comatose, or of an anencephalic infant, is a new form of sustainable human life created by medical technology, and therefore these individuals should not merit the same legal protections as other persons.<sup>87</sup> This argument ignores the fact that a live anencephalic infant is autonomous in a way that the irreversibly comatose patient on artificial life support is not. It is true that death will occur without intervention, but until that point, the anencephalic lives on its own. We do not extinguish a patient's rights simply because they may be ill, or even at death's door.<sup>88</sup> Therefore, if a dying person is accorded rights, then the use of anencephalics as organ donors clearly violates those rights.<sup>89</sup>

### 1. The Right to Bodily Integrity

With this legally conferred status of personhood, the first prohibition against harvesting organs from the live anencephalic

---

84. *Id.* at 163-64. It is not the author's intent to delve into the issues of personhood of a fetus or when life begins. Those questions and others stemming from the abortion debate are a separate set of issues that go far beyond the scope of this Comment.

85. *Crouse Irving Memorial Hosp. v. Paddock*, 485 N.Y.S.2d 443 (Sup. Ct. 1985) (finding that the state's interest in the fetus outweighed the mother's objections to intervention on religious grounds).

86. See 42 U.S.C.A. § 1396a (Hyde Amendment) (West 1992 & Supp. 1994).

87. *Patterson*, *supra* note 71, at 1541-42.

88. *In re A.C.*, 573 A.2d 1235, 1247 (D.C. 1987).

89. *Meilaender*, *supra* note 66, at 23.



infant is the right of bodily integrity. Derived from the inalienable rights of life and limb, it is the right to be free from non-consensual invasion of one's own person. "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."<sup>90</sup>

The right of a person to control his own body is a basic societal concept that provides the foundation for the medical doctrine of informed consent.<sup>91</sup> This doctrine protects a patient's status as a human being, recognizing that all persons have a fundamental right to expect that their lives will neither be foreshortened against their will, nor prolonged painfully and unnecessarily.<sup>92</sup> In this context, the right to bodily integrity is enunciated as having two aspects: the right to consent to medical intervention and the right to refuse it.<sup>93</sup> Not only does the non-consensual organ harvesting from a live infant violate this principle, but artificially prolonging an anencephalic's life in order to preserve its organs represents an unnecessary and possibly painful intervention which confers no benefit upon the child. If it is true, as often asserted, that medical case law is evolving toward greater recognition of patients' rights,<sup>94</sup> then use of anencephalics as donors would constitute a clear legislative and judicial reversal of this trend.

Arising from the same regard for human dignity and self-determination, is the constitutional right to privacy found in the penumbras and emanations of the specific guarantees in the Bill of Rights.<sup>95</sup> If this assurance reaches out to protect the freedom of a woman to terminate her pregnancy under certain conditions, so it encompasses the right of a patient to preserve his or her right to privacy against unwanted infringements of bodily integrity.<sup>96</sup> Those who are incompetent to assert this right, or even to appreciate it, are still entitled to it. The fact that they are unable to speak for themselves on life and death issues concerning their medical treatment does not mean that they lack a right to

---

90. *Union Pacific Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891).

91. *In re Conroy*, 486 A.2d 1209, 1221 (N.J. 1985).

92. *Id.* at 1220 (quoting *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 422 (Mass. 1977)).

93. *Id.* at 1229.

94. *Bartling v. Sup. Ct.*, 209 Cal. Rptr. 220, 224-25 (Cal. Ct. App. 1984).

95. *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965).

96. *In re Quinlan*, 355 A.2d 647, 659 (N.J. 1976) *cert. denied*, 429 U.S. 922 (1976).

self-determination.<sup>97</sup> Rather, when the patient is incompetent to exercise this independent right of choice, it may be asserted on his or her behalf by that person's guardian.<sup>98</sup> Exactly how these rights are asserted and to what degree is dependent upon the doctrine of substituted judgment and the best interest theory.

## 2. Substituted Judgment and Best Interests

The doctrine of substituted judgment requires a surrogate decision-maker to establish, as accurately as possible, what the patient would decide if competent.<sup>99</sup> In its strictest application, determination of what the patient would decide must be based on "clear and convincing evidence of the patient's intent, derived from either a patient's explicit expressions of intent or from knowledge of the patient's personal value system."<sup>100</sup> Courts, in adjudicating cases where the rights of incompetents were at stake, and, particularly where the patients were minors or incompetents who were either incapable of expressing mature or informed preferences, or for whom no personal value system could have been formed, have either modified this standard to accommodate the facts or have adopted the best interest theory.<sup>101</sup> Determination must be made as much as possible in accordance with the presumption of what the incompetent's own decision would be if capable of making it.<sup>102</sup> Consent through substituted judgment is not dependent upon prior expression of a view when competent.<sup>103</sup>

The best interest theory calls for a guardian, in the exercise of his or her judgment, to determine what is best for the ward.<sup>104</sup> As opposed to the doctrine of substituted judgment, which is focused on the presumed wishes of the patient, best interest theory lets a third party (the guardian) make a determination of a patient's quality of life that may or may not comport with what

---

97. *In re Conroy*, 486 A.2d at 1229.

98. *In re Quinlan*, 355 A.2d at 662.

99. *Curran v. Bosze*, 566 N.E.2d 1319, 1324 (Ill. 1990).

100. *Id.*

101. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 427-28 (Mass. 1977).

102. *In re Hier*, 464 N.E.2d 959, 964 (Mass. App. Ct. 1984).

103. *But see, In re Conroy*, 486 A.2d 1209, 1231 (N.J. 1985) (following *In re Storar*, 420 N.E.2d 64, 72 (N.Y. 1981) (must be clear and convincing proof of patient's wishes for substituted judgment to be applied)).

104. *Curran*, 566 N.E.2d at 1334.

that person would have chosen had they been competent.<sup>105</sup> That there may be a tension between the guardian's perception of best interests and the ward's actual common law, statutory, or constitutional rights is freely acknowledged.<sup>106</sup> Certainly this conflict was present in Baby Theresa's case, where her parents, acting in what they saw as the her best interests by trying to make something good come out of her unfortunate life, were guilty of violating Theresa's own rights under Florida's determination of death statutes,<sup>107</sup> and the common law and constitutional rights to privacy and bodily integrity articulated above.

Regardless of which theory is used to support the decision-making process by which an incompetent is protected, the key inquiry is the presence or absence of a benefit to the incompetent.<sup>108</sup> A look at how this principle has been applied in the context of organ donations by minors and incompetents is relevant to deciding the rights of the anencephalic newborn who would be used as a "source" for the benefit of other children in need.

The leading case is *Curran v. Bosze*. The issue was whether 3 1/2-year-old twins should be compelled to undergo compatibility testing for a proposed bone marrow transplant procedure in order to save the life of their 12-year-old half-brother who was suffering from leukemia. The twins had no existing familial relationship with the boy, who was the son of their non-custodial father. Their mother, believing it was not in the twins' best interests, had steadfastly refused to submit them to the procedure.<sup>109</sup>

The Illinois Court was urged by the father to apply a standard of imputed consent under the doctrine of substituted judgment, based upon what the twins might wish were they competent to form an opinion.<sup>110</sup> The court declined. "Since it is not possible to discover that which does not exist, specifically, whether the 3 1/2-year-old twins would consent or refuse to consent to the proposed bone marrow harvesting procedure if they were competent, the doctrine of substituted judgment is not relevant and may not be applied."<sup>111</sup> The court was particu-

---

105. *Id.*

106. *Id.*; *Cf. Saikewicz*, 370 N.E.2d at 428 (the standard of best interest is *not* a reasonable person inquiry).

107. *See supra* section I.

108. *Curran*, 566 N.E.2d at 1331.

109. *Id.* at 1321.

110. *Id.* at 1322.

111. *Id.* at 1326.

larly concerned that the procedure would be dangerous and painful to the potential donor, and also that the custodial parent was opposed to the operation and therefore her reservations might somehow be communicated to the twins, exacerbating the psychological trauma. That there was no relationship between the twins and the child to be benefited was an additional factor. In its ruling, the court held that a parent or guardian may give consent on behalf of a minor child to donate bone marrow to a sibling only when to do so would be in the best interest of the minor.<sup>112</sup>

*Curran v. Bosze* followed an earlier line of cases in its application of the doctrine of substituted judgment and best interest theory, but the results have not always been consistent. In no case, however, has a court ordered organ donation for the benefit of a third party without a clear finding that forced submission to such a procedure would be in the best interests of the organ donor.<sup>113</sup>

### C. Public Policy Interests in Protecting the Infant with Anencephaly

The constitutional right to privacy may be overcome where the State can show a compelling interest that would justify overruling the individual's right to privacy,<sup>114</sup> and certainly the overwhelming need for usable organs for pediatric transplants qualifies as a compelling interest. It is tempting to view harvesting organs from live anencephalic newborns as a partial

---

112. *Id.* at 1331.

113. *Accord*, *Strunk v. Strunk*, 445 S.W.2d 145, 146 (Ky. 1969) (ordering kidney donation from mental incompetent to his brother after determination that incompetent was emotionally and psychologically dependent upon him and his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney; dissent argued that the ability to fully understand and consent is a prerequisite to the donation of a part of the human body); *Little v. Little*, 576 S.W.2d 493, 500 (Tex. 1979) (applying substituted judgment to allow kidney donation, but stating, "Nothing in this opinion is to be construed as being applicable to a situation where the proposed recipient is not a parent or sibling of the incompetent."); *Hart v. Brown*, 289 A.2d 386 (Conn. 1972) (following *Strunk* in allowing mentally incompetent 27-year-old to donate kidney to her twin sister). *But see*, *Guardianship of Pescinski*, 226 N.W.2d 180 (Wis. 1975) (declining to apply substituted judgment absent real consent); *accord*, *In re Richardson*, 284 So. 2d 185, 187 (La. App. 1973) (refusing to allow donation under best interest theory without a showing that the donation would, "protect and promote the ultimate best interest of the minor").

114. *Griswold v. Connecticut*, 381 U.S. 479, 485 (1965).

solution to alleviate the serious shortage.<sup>115</sup> This interest is not so compelling, however, as to justify sacrificing the anencephalic infant's fundamental and constitutionally guaranteed right to life.<sup>116</sup> Changing the laws on determination of death, whether by excluding the anencephalic newborn altogether, or by broadening them to adopt the neocortical standard so that an anencephalic would fit within the new definitional framework, is troubling in that it just is not that simple. The public policy interests that would be violated are wide ranging, and serious. "Treating as the subject does with irreversible decisions affecting life and death, we approach, and even may be thought by some to trespass on, the domain of Providence."<sup>117</sup>

The State's interest in protecting the lives of its citizens is paramount. In keeping with that interest, in the medical arena there are a number of settled public policy exceptions where the individual right to privacy may be overcome.<sup>118</sup> The State may for example, require that citizens submit to medical procedures in order to eliminate a health threat to the community.<sup>119</sup> The State may, by statute, prohibit individuals from engaging in specified activities, including medical procedures which are inherently hazardous to their lives.<sup>120</sup> It may prohibit a patient from choosing a particular course of treatment which would lead to death, in the interest of upholding its homicide laws<sup>121</sup> or preventing suicide.<sup>122</sup> The State also has a *parens patriae* interest in protecting a patient's minor children from "abandonment" by the parent, however, the State's interest in the protection of third parties is minimal or nonexistent compared to the rights of the patient.<sup>123</sup> Finally, and particularly in the right to die context, the State has an interest in protecting the medical profession's desire to act affirmatively to save life without fear of civil liability.<sup>124</sup> Not only do none of these judicially created public policy exceptions act to overcome the State's compelling

---

115. Julius Landwirth, *Should Anencephalic Infants be Used as Organ Donors?*, 82 PEDIATRICS 257 (1988).

116. U.S. CONST. amend. XIV, sec. 1.

117. *In re Storar*, 420 N.E.2d 64, 75 (N.Y. 1981).

118. *Id.* at 71.

119. *E.g.*, *Jacobson v. Massachusetts*, 197 U.S. 11, 37 (1905).

120. *E.g.*, *Roe v. Wade*, 410 U.S. 113, 154 (1973).

121. *In re Storar*, 420 N.E.2d at 71.

122. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 423 (Mass. 1977).

123. *Id.*; *See also*, *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713 (Conn. 1984); *JFK Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984).

124. *Saikewicz*, 370 N.E.2d at 423.

interest in protecting the anencephalic newborn's inalienable right to life and liberty, but the second, third, and last stated interests clearly apply to prohibit organ harvesting from the live infant.

Beyond the obligation to protect the liberty of its citizens, changing the determination of death law treads upon the State's awesome power and responsibility under the doctrine of *parens patriae*, to care for and protect the best interests of the incompetent person.<sup>125</sup> Public policy demands legal protection of the personal rights of individuals who are incapable of intelligent decision, and even where consent may have been given, the court is not precluded from intervening when it determines that consent was not made with sufficient understanding of the consequences of the decision.<sup>126</sup> "Where particularly important personal interests are at stake, clear and convincing evidence should be required [before those interests can be sacrificed]."<sup>127</sup>

The State has a further interest in protecting the ethical integrity of the medical profession.<sup>128</sup> As the previous discussion in Section II illustrates, not only is the exact nature of anencephaly still somewhat of a question, but the views on what constitutes ethical treatment of anencephalic infants are widely disparate, and reflect fundamental unease with the varying hypotheses on the nature of life and death in the anencephalic.<sup>129</sup> The proposed statutory changes, while settling the issue of criminal and civil liability, would do nothing to solve the underlying moral dilemma experienced by many doctors, nurses and families. Also, if the doctrines of informed consent and right of privacy have as their foundation the right to bodily integrity then those rights are superior to the institutional considerations.<sup>130</sup> Ultimately, our system approaches all persons as if they have equal worth. The State has an obligation to not undermine that principle, no matter how noble the justification.

### III. PARENTAL RIGHTS AND THE ANENCEPHALIC NEWBORN

#### A. Parental Rights and Decision-making

*Once Campo made her decision to carry Theresa to term, the wheels were set in motion. Her own doctors told her there was*

---

125. *Id.* at 427.

126. *Bonner v. Moran*, 126 F.2d 121, 121 (D.C. Cir. 1941) (finding minor child's consent to the donation of skin graft for the benefit of another to be inadequate).

127. *In re Storar*, 420 N.E.2d at 72.

128. *Saikewicz*, 370 N.E.2d at 426.

129. See discussion *supra*, section II.

130. *Saikewicz*, 370 N.E.2d at 426.

only a 20 percent chance that Theresa would be born alive, and even then the odds of her remaining alive long enough for her organs to be of any use were 50/50. Campo and Pearson were in agreement however. They believed this was the right thing to do, and when Theresa was born, they requested that she be declared legally dead to facilitate harvesting her organs. The hospital, out of concern over civil or criminal liability, refused.<sup>131</sup>

The couple's attorney, Scott Mager, argued that the Florida statute requiring total brain death represented a Catch-22. "If you wait until the infant is legally dead under the statute to remove its organs," he asserted, "then the organs are dead. It's pointless."

After filing an emergency appeal in the Florida court, Mager presented Florida Senate Majority Leader Pete Weinstein with a handwritten draft of proposed legislation that would declare anencephalic babies dead upon birth or when they stop breathing on their own. In both cases, parents would have to give their written permission for organ donation, and if the organs were not removed within seven days, the baby would be removed from life support machines and allowed to die naturally.<sup>132</sup> As the family and their attorneys explained their goal of conferring life on as many children as possible, their proposal made perfect sense. Laura Campo and Justin Pearson had not made their decision lightly.

"The child of man is his parent's child and not the State's."<sup>133</sup> Should the parents then, be denied the freedom to decide the best course of action to mitigate the tragedy of anencephalic birth in their own family? By denying their ability to make usable organs available for donation, are we robbing them of the one of the few options they might have? Is our justification for this denial merely practical—that to do so would further confuse an already complicated issue—or is it based on the speculative "slippery slope" argument? Is there a more compelling societal interest at stake?

The answer is that we do not want to restrict parental authority, but we must. Basic rights are indicative of the moral structure of societal inter-individual relationships. Although any

---

131. *In re T.A.C.P.*, 609 So. 2d 588, 589 (Fla. 1992).

132. Rick Bragg, *The Life and Death of Theresa Ann*, THE OTTAWA CITIZEN, Apr. 3, 1992, at C5.

133. *Pierce v. Society of Sisters*, 268 U.S. 510, 518 (1925).

harm that may come from interference may seem justifiable or trivial, as long as the action is deliberate, and the damage manifest, there can be no compromise.<sup>134</sup> It is this very certainty that fills the vacuum in our legal structure that occurs as a natural consequence of advancements in medical technology and practice. By recognizing the absolute character of basic rights, we can navigate the most difficult issues in bio-ethics with confidence, knowing that our decisions are morally connected with what has gone before.<sup>135</sup> We do not have to make the excruciating, case-by-case analysis that our judicial system was not designed to effectively handle, and which leads only to further uncertainty. Because basic rights are absolute, the law cannot allow parents to deprive any child of life solely for the purpose of harvesting its organs. Parents do play a unique role in decision-making, but there are limits to their discretion, even in extreme cases such as that of the anencephalic.

"The primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition."<sup>136</sup> Thus, the state can generally only come between child and parent when there is a clear and convincing showing of child abuse or neglect.<sup>137</sup> As applied in the medical context, parents have, under the doctrine of substituted judgment or best interest theory,<sup>138</sup> the right to validly assert a privacy interest on behalf of the child to impose<sup>139</sup> or refuse treatment,<sup>140</sup> or even order discontinuance of the child's life support systems.<sup>141</sup> Because the Supreme Court has not decided whether the right to liberty encompasses an explicit "*right*" to die,<sup>142</sup> where the state claims an interest in maintaining life support, courts will scrutinize the decision to withhold or terminate treatment for an incompetent very carefully.<sup>143</sup> As the court in the well-known case of Karen Ann Quinlan stated, quoting Bishop Lawrence B. Casey:

---

134. STOLJAR, *supra* note 73, at 95.

135. *Id.* at 96-97.

136. *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972).

137. *In re Baby K*, 832 F. Supp. 1022, 1031 (E.D. Va. 1993).

138. *See* discussion *supra* sections II.B.1., II.B.2.

139. *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941).

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

141. *Id.*; *In re Quinlan*, 355 A.2d 647, 664-67 (N.J. 1976); *In re Jane Doe*, 418 S.E.2d 3, 3 (Ga. 1992).

142. *Cruzan v. Director, Missouri Dep't. of Health*, 497 U.S. 261, 277-79 (1990) (refusing to decide this question) (emphasis added).

143. *See e.g., In re Jane Doe*, 418 S.E.2d 3 (Ga. 1992); *Cruzan*, 497 U.S. at 270-75.



It is both possible and necessary for society to have laws and ethical standards which provide freedom for decision, in accord with the expressed or implied intentions of the patient, to terminate or withhold extraordinary treatment in cases which are judged to be hopeless by competent medical authorities, without at the same time leaving an opening for euthanasia.<sup>144</sup>

The moral and legal underpinning of such decisions continues to be the belief that parents are acting in the best interests of their child. Thus, a decision to redefine death so as to shorten the life of a terminally ill newborn in order that its organs can be removed would create a major exception which, no matter how altruistic the motives behind it, raises troubling questions about the extent of parental power.

The argument that parental consent should govern also presumes that both parents can agree about what should be done with their child. In fact, there are not only numerous cases where the parents were in total disagreement, but at a time when almost one in three live births in this country are out of wedlock,<sup>145</sup> the issue of conflicting rights is sure to rise. In both of the two most recently litigated cases regarding treatment of anencephalic newborns, *In re T.A.C.P.*, and *Matter of Baby K*, the parents were unmarried, and Baby K's biological parents did not agree on what was to be done with her.<sup>146</sup> The court in *Baby K*, following a Georgia case of substituted judgment where the parents were also in disagreement,<sup>147</sup> ruled that if one parent asserts the child's explicit constitutional right to life as the basis for continuing medical treatment, and the other is claiming the less specific liberty interest in refusing life-saving treatment on behalf of a minor child, the explicit right to life must prevail.<sup>148</sup>

Furthermore, the constitutional right of privacy is the child's. It is not a constitutional right of the parent.<sup>149</sup> The only parental right of privacy specifically recognized under the Constitution is the right to direct the upbringing and education of children under their control.<sup>150</sup> Therefore, the state, under its authority as *parens patriae*, does have wide-ranging power to limit parental freedom

---

144. *In re Quinlan*, 355 A.2d at 659-60.

145. U.S. BUREAU OF THE CENSUS, STATISTICAL ABSTRACT OF THE U.S. (113th ed. 1993).

146. *In re Baby K.*, 832 F. Supp. at 1030.

147. *In re Jane Doe*, 418 S.E.2d 3 (Ga. 1992).

148. *In re Baby K.*, 832 F.Supp. at 1030.

149. *In re Quinlan*, 355 A.2d at 662.

150. *Yoder*, 406 U.S. at 232 (affirming *Pierce*, 268 U.S. at 534).

and authority in things affecting the child's welfare.<sup>151</sup> This is not a balancing of interests. Rather it should be read as a clear recognition that the parents' general rights, and duty of care, are limited when the child's basic, or natural rights, are threatened. If the law is actually changed to declare the anencephalic infant dead, or to specifically exclude it from the definition of live birth, an immediate conflict arises. Not only would the infant's welfare and right to life be sacrificed in favor of parental discretion, but such a law would leave the child unprotected even where the parents wish to assert its life interest.

Parental consent clauses as a precursor to donating the infant's organs are not the solution, for they serve only to avoid conflicts regarding the disposition of the cadaver. The basic issue would be unresolved. If a parent believes that his or her breathing, functioning child is alive, then statute or no, he or she will try, and indeed is morally compelled, to protect that child from a premature determination of death. If the law upholds this obligation, how can it also uphold the parent who wishes to invoke an arbitrary determination of death in the same type of case in order to facilitate organ donation? How could we justify such a gross inconsistency? Whose interests should prevail?

There may also be a legitimate question as to whether the parents are capable of making a decision that is truly in the best interest of the child in this situation. Some may argue that judgment as to whether the child should be declared legally dead should be left solely to legislators, doctors, and judges, but the law presumes, "[N]atural bonds of affection, lead parents to act in the best interests of their children."<sup>152</sup> However, the parents are also the most emotionally involved, and the risk is great that their judgment may be clouded by their own pain and suffering.<sup>153</sup> The recent cases of Baby Theresa<sup>154</sup> and Baby K<sup>155</sup> are illustrative

---

151. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

152. *In re L.H.R.*, 321 S.E.2d 716, 723 (Ga. 1984) (quoting *Parham v. J.R.*, 442 U.S. 584, 602 (1979)).

153. *In re A.C.*, 573 A.2d 1235, 1250 (D.C. 1990) (cautioning in dicta that while in the majority of cases family members will have the best interests of the patient in mind, sometimes they will rely on their own judgments or predilections).

154. *In re T.A.C.P.*, 609 So. 2d 588 (Fla. 1992).

155. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993) (*In re Baby K* is, as of the writing of this comment, the most recent litigation regarding treatment of an infant with anencephaly. In a remarkable development, Baby K lived, in an institution, for over a year with the only medical intervention being emergency resuscitation. The issue in her case was whether the hospital where she was taken for emergency care was forced to resuscitate her even though such actions were in contravention to established treatment

of parents on either end of the spectrum in evaluating the options available to them regarding medical care for their anencephalic newborns. In Baby Theresa's case, her parents were so determined to "make her life count for something,"<sup>156</sup> that they were willing to ignore Theresa's rights in order to harvest her organs for transplant. On the other hand, Baby K's mother, Ms. H, was adamant that her daughter be kept alive at all cost, even to the point of ordering emergency artificial respiration solely for the purpose of ensuring that Baby K would die, what she believed to be, a "natural" death.<sup>157</sup> In both cases, the parents' wishes fell outside of standard medical treatment, and the attending physicians were in opposition.<sup>158</sup> No one doubts the sincerity of these parents' love for their children or the depth of their sorrow. However, one is led to question how well equipped they were, under such extreme emotional influences, to make decisions that would deprive a newborn of its inalienable right to life.

### *B. Checks and Balances - The Role of Physicians and the Courts*

Recognizing the fundamental interests at stake, life and death decision-making procedures are established so that the parents never act autonomously. "Decision-making within health care, if it is considered as an expression of a primary obligation of the physician, *primum non nocere* (first do no harm), should be controlled primarily within the patient-doctor-family relationship."<sup>159</sup> Attending medical personnel have an interest, not only in protecting the integrity of their own profession,<sup>160</sup> but because they must execute the treatment commensurate with any decision regarding the fate of the anencephalic newborn. The doctor's role has become especially difficult, as he or she must often act, in effect, as the ultimate arbiter. Since developments in medical technology have obfuscated the use of the traditional definition of death, when dealing with alternatives to the cardiopulmonary

---

protocols for anencephalics. The District Court, relying on statutory interpretation of the Americans with Disabilities Act, ruled that it was. In forcing this action, Baby K's mother, Ms. H., was relying on her own religious belief that all life is sacred.)

156. Rick Bragg, *The Life and Death of Theresa Ann*, THE OTTAWA CITIZEN, Apr. 3, 1992, at C5.

157. *In re Baby K*, 832 F. Supp. at 1025.

158. *Id.* at 1024; *In re T.A.C.P.*, 609 So. 2d at 589.

159. *In re Quinlan*, 355 A.2d 647, 669 (N.J. 1976).

160. See discussion *supra* section II.C.

standard the patient's condition can be determined only by a physician.<sup>161</sup>

"The doctor, however, has no right independent of the patient."<sup>162</sup> He must act under medical standards and legal constraints.<sup>163</sup> Because there is great disagreement among physicians as to the nature of anencephaly, medical staffs are already in an untenable position legally and ethically with regard to treatment of a live born anencephalic infant. "Medical science is not authorized to directly cause natural death; nor however, is it expected to prevent it when it is inevitable and all hope of a return to an even partial exercise of human life is irreparably lost."<sup>164</sup> Statutory change might solve some of the problems of civil and criminal liability, but it would not change the underlying ethical questions. Quite the reverse would be true, for it would establish a precedent that would be in contravention to the physician's primary obligation—the well-being and best interests of the patient.

"The right to a natural death is one outstanding area in which the disciplines of theology, medicine and law overlap; or, to put it another way, it is an area in which these three disciplines convene."<sup>165</sup> It is inevitable that conflicts among all parties will arise as they struggle in making life and death decisions. However, it is only the fact that our system of law does recognize certain irrefutable principles, such as the existence of inalienable rights, that makes it possible to maintain a consistent position that will guard the interests of those most in need of protection. Where unresolvable differences do arise, the only recourse the interested parties have is the court.<sup>166</sup> But in this particular area, "the problem is one which the judicial system is unsuited and ill-equipped to solve and which should not usually be made the subject of judicial attention."<sup>167</sup>

The legal system is a cumbersome route by which to attain a determination in a life and death decision. The exigencies of the circumstances require immediate adjudication, yet the same factor makes it extremely difficult, each decision "depending as it necessarily must not only on medical data, but on theological

---

161. *In re Quinlan*, 355 A.2d at 656.

162. *Id.* at 658.

163. *Id.* at 656.

164. *Id.* at 659.

165. *Id.*

166. *In re Jane Doe*, 418 S.E.2d 3, 7 (Ga. 1992).

167. *In re Storar*, 420 N.E.2d 64, 75 (N.Y. 1981) (Jones, J., dissenting).

tenets and perceptions of human values which defy classification and calibration."<sup>168</sup> As the Appeals Court said in *In re A.C.*, overturning the trial court's finding *after* the patient had already died:

We observe nonetheless that it would be far better if judges were not called to patients' bedsides and required to make quick decisions on issues of life and death. Because judgment in such a case involves complex medical and ethical issues as well as the application of legal principles, we would urge the establishment—through legislation or otherwise—of another tribunal to make these decisions, with limited opportunity for judicial review.<sup>169</sup>

"The methodology and techniques for our classic adversary system are not best suited to the resolution of such issues."<sup>170</sup>

The law as it currently stands is fairly clear-cut. The "catch-22" referred to by Laura Campo's attorney does exist, but it is based in natural law as well as modern American jurisprudence. The proposed change, however, is not. It presumes rights and interests that do not exist—a societal right to a person's organs, a parental right to declare that a dying child is already dead solely for the benefit of another—in short, it is an emotional argument with no foundation. By giving legal recognition to these interests through legislative adoption of a different standard for the determination of death, or creation of the specific exception for anencephaly, our system, which values the life of the individual above all else, would be turned on its head. The courts would continue to be the only recourse, because parents and doctors could find themselves caught in a new catch-22. This one, however, unlike the one in which Baby Theresa's parents found themselves, would carry a presumption of death, not a presumption of life.

## VI. THE CALL FOR COMPROMISE: IS THERE A LEGITIMATE BASIS FOR A BALANCING APPROACH?

Is there a legitimate case for a balancing approach that compares and adjudicates the rights of the anencephalic newborn and the needs of another terminally ill yet potentially curable

---

168. *Id.*

169. *In re A.C.*, 573 A.2d 1235, 1237 n.2 (D.C. 1990) (citing *Satz v. Perlmutter*, 379 So. 2d 359, 360 (Fla. 1980)).

170. *In re Storar*, 420 N.E.2d at 75 (Jones, J., dissenting).

child? The authority of the parents, and the rights of the infant? The answer to these questions is a resounding "no."

The harm or pain inflicted on a nobody must be judged as seriously as injury to the highest . . . [for] while it is not imperative to the notion of equality that all human beings are alike, it is critical that we accept that all are protected from interference or compulsion. If we fail to recognize this personal immunity, then we undercut the societal foundation of equality that protects the weak from the strong.<sup>171</sup>

The current definitions of death provide a bright line test. It is not perfect. There is still much doubt about its application. All too often, grieving family members find themselves alone in their frustration, waiting for an inevitable death to occur or hoping against hope that a prognosis of brain death was wrong. But the purpose of the standard is clear to all. It is a test that protects the patient to the maximum extent realistically possible. This is not a place where a balancing of interests should occur.

The dilemma faced in cases such as Baby Theresa's has been characterized as an issue of Kantian versus utilitarian ethics. The utilitarian ethic can be summed up by the slogan, "the greatest good for the greatest number."<sup>172</sup> Kantian ethics, on the other hand, would prohibit using one person for the sake of another.<sup>173</sup> It is an important, but not easily definable principle that recognizes the value of individual autonomy and human life, no matter how short, or how outwardly burdensome. American society, while placing some demands upon the individual in the interests of accommodation and order, still basically adheres to the Kantian ethic. Indeed, this is readily apparent when one looks at the structure of our criminal justice system.

Under our adversary system, the interests of the state are not absolute, or even paramount. The dignity of the individual is respected to the point that even when a citizen is known by the state to have committed a heinous offense, the individual is nevertheless accorded such rights as counsel, trial by jury, due process, and the privilege against self-incrimination.<sup>174</sup>

---

171. STOLJAR, *supra* note 73, at 85-86.

172. Charles Krauthammer, *Five Babies vs. One Principle; Which is Worth More?*, THE WASH. POST, Dec. 11, 1987, at A27.

173. *Id.*

174. Monroe H. Freedman, *Judge Frankel's Search for Truth*, 123 U. PA. L. REV. 1060, 1063 (1975).

In tort law, this is most readily seen in the doctrine of no duty to rescue, a principle that is deeply ingrained in the Uniform Anatomical Gift Act.<sup>175</sup>

Because we as a society adhere to the Kantian ethic, to shorten the life of an infant with anencephaly creates a dangerous inconsistency. We do not end doomed lives prematurely. Our current definitions of death have been carefully crafted to protect the rights of the living, regardless of how near death they might be.

[I]n virtually all cases, the decision of the patient, albeit discerned through the mechanism of substituted judgment, will control. We do not quite foreclose the possibility that a conflicting state interest may be so compelling the patient's wishes must yield, but we anticipate that such cases will be extremely rare and truly exceptional.<sup>176</sup>

Harvesting the organs of living, breathing anencephalic newborns has no place in this framework. In spite of the good intentions behind the idea, it would represent a major departure into a utilitarian scheme.

It has been argued that to make a single exception in the law for the anencephalic is not enough to lead us down the slippery slope toward making organ farms of other terminally ill, or seriously defective patients.<sup>177</sup> This begs the question. Bioethics poses new challenges every day, and in response, there is a compelling need for the law to respect basic rights and adhere to settled standards regardless of the sympathies that are raised in a single case. On the scale of life and death, certain lines have been drawn. Personhood has been conferred upon live birth, a compelling state interest has been established at the point where a fetus becomes viable.<sup>178</sup> These lines are not always clear, but they are consistently marked on one side of the spectrum—the moment of birth and the period of potential life that precedes it. Any change in the law that would accommodate organ harvesting from a live anencephalic infant, creates a point on this spectrum that is inconsonant with these previous decisions. It would declare that there is a point on the “life” side where inalienable rights could be taken away, or completely denied. This is the inconsis-

---

175. UNIFORM ANATOMICAL GIFT ACT, 8a U.L.A. § 2 (1993).

176. *In re A.C.*, 573 A.2d 1235, 1252 (D.C. 1990).

177. *See, e.g.*, Friedman, *supra* note 8, at 973; Truog & Fletcher, *supra* note 8, at 389.

178. *Roe*, 410 U.S. at 163.

tency that leads to the slippery slope, and no matter who makes the decision on behalf of the live-born anencephalic, or by what process early death would be declared, the bright line in our law between life and death would be irretrievably broken. Before taking such a step, in either our legislatures or our courts, we must step back and remind ourselves of the fundamental values involved, and the importance to our system of their inalienable nature.

Some would say Baby Theresa's life was wasted. They would point to the statistics covering infant deaths for the year 1992, and speculate as to which of those could have been avoided had one of her tiny organs been available for transplant. They would argue that without this ability to give life to others, Theresa's birth itself was a tragic mistake, but that is hardly the case. On the contrary, the short life of Theresa Ann Campo-Pearson serves as a reminder that, amidst the often de-humanizing miracle of modern medical technology, and an increasingly complex legal system, the idea of the basic dignity possessed by every human being has not been lost, subverted, or drowned in a complicated sea of good intentions. Baby Theresa touched off an important debate. Few among us will leave such a valuable legacy.

#### EPILOGUE

*On March 30, 1992, after nine days spent clinging to the only life she'd ever known, Theresa Ann passed away. Her loss was greatly mourned.*

MICHELLE A. HUGHES