
NOTES

THE USE OF ANENCEPHALIC INFANTS AS AN ORGAN SOURCE: AN ON-GOING QUESTION

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“In an absolute sense, no one can ever know what is ultimately the right choice: we simply cannot forecast the future.”²

INTRODUCTION

“The condition of anencephaly has attracted considerable . . . attention in medical, legal, ethical, religious, and lay discussions”³ over the past two and a half decades, and as a result many have begun to study these infants and the numerous issues that arise from their existence. One of those on-going issues is whether infants born with anencephaly could and/or should be used as an organ source for other infants.

While anencephaly is a fairly well-documented and distinct condition,⁴ few individuals in the public have ever heard of it, let alone explain what it is. It has been defined by the Medical Task Force on Anencephaly as “a congenital absence of a major portion of the brain,

¹ J.D., Elon University School of Law. Special thanks to Professor Helen Grant, who was a wonderful sounding board for my ideas, and who really helped me in the final stages of writing by taking the time to give exceptionally helpful suggestions and critiques.

² Jennifer S. Bard, *The Diagnosis is Anencephaly and the Parents Ask About Organ Donation: Now What? A Guide for Hospital Counsel and Ethics Committees*, 21 W. NEW ENG. L. REV. 49, 80-81 (1999).

³ David A. Stumpf et al., *The Infant with Anencephaly*, 322 NEW ENGL. J. MED. 669 (1990).

⁴ *In re T.A.C.P.*, 609 So. 2d 588, 590 (1992).

skull, and scalp, with its genesis in the first month of gestation.”⁵ The condition is generally diagnosable when four criteria are met: “1) a large portion of the skull is absent, 2) the scalp, which extends to the margin of the bone, is absent over the skull defect, 3) hemorrhagic, fibrotic tissue is exposed because of defects in the skull and scalp, 4) recognizable cerebral hemispheres are absent.”⁶ The infants are usually born with “protruding eyeballs . . . ears [that] are malformed, and the neck is extremely short.”⁷ However, there is usually a recognizable portion of the brain stem that “enables the heart and lungs to function for a short time.”⁸

Ninety-five percent of parents⁹ decide to abort the pregnancy once a diagnosis of anencephaly is made because many consider the condition to be “incompatible with life.”¹⁰ Despite this, approximately one in every 4,000 infants is carried to term and is born with anencephaly.¹¹ Most infants that are born die within days of birth, with only a small percentage surviving past the first week of life.¹² Anencephalic infants suffer from “a lack of brain development above the brain stem.”¹³ Death is brought about due to minimal brain activity

⁵ Stumpf, *supra* note 3, at 669. This means that the infant is born without a very large portion of its brain; however it does not mean there is a complete absence of a brain or brain activity. *See id.*

⁶ *See* Stumpf, *supra* note 3, at 670.

⁷ Debra H. Berger, *The Infant with Anencephaly: Moral and Legal Dilemmas*, 5 ISSUES L. & MED. 67, 68 (1989-1990). It usually develops within the first couple of months of the pregnancy and can be diagnosed in utero through the use of ultrasound equipment and after the infant has been born through a visual inspection of the infant. The cause of the condition is virtually unknown; however, “data suggest a polygenic or multifactorial etiology” in addition to possible maternal factors, “including hyperthermia and deficiencies of folate, zinc, and copper.” Stumpf, *supra* note 3, at 670.

⁸ Sue A. Meinke, *Anencephalic Infants as Potential Organ Sources: Ethical and Legal Issues* 2 (June 1989), available at <http://bioethics.georgetown.edu/publications/scopenotes/index.html>.

⁹ *Id.*

¹⁰ Fazal Khan & Brian Lea, *Paging King Solomon: Towards Allowing Organ Donation from Anencephalic Infants*, 6 IND. HEALTH L. REV. 17, 20 (2009).

¹¹ *See Facts about Anencephaly*, CTRS. FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/ncbddd/birthdefects/Anencephaly.html> (last visited Sept. 21, 2011). This number has been decreasing since the late 1980s but has essentially become stagnant. *See* T.J. Matthews, *Trends in Spina Bifida and Anencephalus in the United States, 1991-2006*, CTRS. FOR DISEASE CONTROL AND PREVENTION, http://www.cdc.gov/nchs/data/hestat/spine_anen/spine_anen.htm (last updated Apr. 29, 2009).

¹² Stumpf, *supra* note 3, at 671.

¹³ Meinke, *supra* note 8, at 2. Breathing and heartbeat actually become sporadic almost immediately after birth and eventually cease altogether. Khan & Lea, *supra* note 10, at 20.

resulting from this lack of brain development, which leads to the heart and lungs becoming unable to function.¹⁴ This lack of brain development also prohibits consciousness from occurring in anencephalic infants.¹⁵ In essence, they are “permanently unconscious because they lack the cerebral cortex necessary for conscious thought . . . similar to those in a persistent vegetative state,”¹⁶ but with a different prognosis.

A diagnosis of anencephaly, and its corresponding lack of consciousness, creates a myriad of complex issues for parents, practitioners, and theorists to ponder. “For parents . . . [it] foretells the ultimate death of their child. For a medical staff . . . [it] means presiding over an infant’s death rather than . . . life. For hospital counsel . . . [it] triggers . . . legal and ethical issues that must be resolved quickly.”¹⁷ The main dilemma for anencephalic infants is their ability to function “without medical intervention,”¹⁸ but their inability to sustain that functioning for very long.¹⁹ This leads to difficulty in qualifying as organ donors.²⁰ For anencephalic infants to “be considered for organ donation . . . [they] must be deemed . . . dead;”²¹ however, once this has occurred in anencephalic infants, the organs are usually already destroyed from a lack of oxygen.²²

Some proponents²³ of using anencephalic infants as an organ source propose using life-support measures to preserve the baby’s organs for transplantation by keeping the blood and air flowing.²⁴ How-

¹⁴ See Meinke, *supra* note 8, at 2 (“The cerebrum, the cerebellum, and often the bones of the skull are absent. However, there is still brain stem activity, which enables the heart and lungs to function for a short time.”).

¹⁵ Khan & Lea, *supra* note 10, at 20.

¹⁶ *Id.* (internal quotation marks omitted).

¹⁷ Bard, *supra* note 2, at 54.

¹⁸ Lisa E. Hanger, *The Legal, Ethical, and Medical Objections to Procuring Organs from Anencephalic Infants*, 5 HEALTH MATRIX 347, 349 (1995).

¹⁹ See *id.*

²⁰ See *id.* at 348.

²¹ Bard, *supra* note 2, at 54. Bard only mentions brain death; however, cardio-pulmonary death is another standard that can be used to determine death. See UNIF. DETERMINATION OF DEATH ACT § 1, 12A U.L.A. 781 (2008). This topic is discussed more fully later in this note.

²² See Kathleen L. Paliokas, *Anencephalic Newborns as Organ Donors: An Assessment of “Death” and Legislative Policy*, 31 WM. & MARY L. REV. 197 (1989); see also Andrea K. Scott, *Death unto Life: Anencephalic Infants as Organ Donors*, 74 VA. L. REV. 1527, 1548-49 (1988).

²³ See Scott, *supra* note 22, at 1547 (suggesting cooling the infant’s temperature to ensure organ viability); see also Hanger, *supra* note 18, at 365 (proposing various methods for maintaining organ viability in anencephalic infants).

²⁴ See Hanger, *supra* note 18, at 365-66.

ever, is this simply prolonging the inevitable? If the infants are not conscious, do they feel pain? Can they feel emotion? Are they even alive? Additionally, if the infant is in fact alive, how can he or she be an organ donor without making a conscious decision to donate and without actually being dead? All of these questions are very complex and have vast implications on the current and future status of anencephalic infants as an organ source. This note will address some of these questions in an effort to show that using anencephalic infants as a source for organs is not a viable option for our society at this point in time.

ORGAN DONATION IN THE UNITED STATES

“The first successful human transplant was performed in 1954 when Dr. Joseph Murray transplanted a kidney from a live donor into his identical twin brother.”²⁵ Transplants during this time had a low success rate due to “rejection and poor organ quality.”²⁶ Improvements came about when a new definition for death, based on neurological death as opposed to a cardio-pulmonary death, was developed.²⁷ This, along with other medical advances, altered the prognosis for organ recipients immensely. Fast-forward half a century and the need for organs in the United States has grown astronomically.²⁸ Currently, over 112,150 people are on the national transplantation waiting list,²⁹ over 7,000 people died while waiting for an organ in 2009,³⁰ and over 1,500 people were unable to receive a transplant due to worsening

²⁵ Maxine M. Harrington, *The Thin Flat Line: Redefining Who is Legally Dead in Organ Donation After Cardiac Death*, 86 DENV. U. L. REV. 335, 339 (2009).

²⁶ *Id.* at 339-340. A big reason for this growth is the improvement of technology and medicine and the discovery of immunosuppressants like cyclosporine. These are thought to be the key to modern organ transplantation success because they lower the rate of organ rejection and improve the standard of living of organ recipients. Harrington, *supra* note 25, at 343.

²⁷ See Berger, *supra* note 7, at 74.

²⁸ Between 1988 and 2006, the number of registrants for organ donation rose from 16,000 to 101,000. See HALL, BOBINSKI, & ORENTLICHER, *HEALTH CARE LAW AND ETHICS* 644 (7th ed. 2007).

²⁹ UNITED NETWORK FOR ORGAN SHARING, <http://www.unos.org/> (last visited Sept. 19, 2011).

³⁰ *Reported Deaths and Annual Death Rates Per 1,000 Patient-Years at Risk Waiting List*, U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES (May 4, 2009), http://www.ustransplant.org/annual_reports/current/106_dh.htm.

health conditions.³¹ In contrast, from January to July 2010, there were only 8,477 donors willing to donate organs.³²

The need for small organs for infants and children is even more problematic than the need for adult organs³³; some consider the lack of organs the “greatest issue currently facing pediatric transplantation.”³⁴ As of October 2010, 706 children under the age of five were placed on the national donor list in need of a kidney, liver, heart, lung(s), pancreas, or intestine.³⁵ The survival rate one year after transplantation hovers around 80-85% for heart transplants, 92% for kidney transplants, and 78-81% for liver transplants.³⁶ The number of lung transplants is so low for children under the age of five that survival rates cannot be calculated.³⁷ Transplantation is often the only option for children with anencephaly and with such a limited supply of small organs, the need for organs is great. Most organs for infants come from others that have died as a result of child abuse, Sudden Infant Death Syndrome (SIDS), and infants born with anencephaly.³⁸ The first two categories do not really provide any organs to speak of,³⁹ leaving anencephalic infants as the only feasible source for small organs.⁴⁰

ORGAN DONATION AND ANENCEPHALIC INFANTS

The history of anencephalic infants and their treatment after birth has been in flux over the past couple of decades. Until the 1960s, babies born with anencephaly were “thought to be so ghastly that they were put in a corner after birth . . . [and] parents might have been told

³¹ See HALL ET AL., *supra* note 28, at 644.

³² See UNITED NETWORK FOR ORGAN SHARING, *supra* note 29.

³³ See Joseph N. Harden, *The “Gift” of Life: Should Anencephalic Infants Die to Serve Noble Goals?*, 27 CUMB. L. REV. 1279, 1283-84 (1996).

³⁴ Bard, *supra* note 2, at 57.

³⁵ See HEALTH RESOURCES AND SERVICES ADMINISTRATION, OPTN Organ by Age Current Waiting List Table, <http://optn.transplant.hrsa.gov/latestData/rptData.asp> (last visited Oct. 29, 2010).

³⁶ See HEALTH RESOURCES AND SERVICES ADMINISTRATION, OPTN All Kaplan-Meier Graft Survival Rates for Transplants Performed: 1997-2004: Survival by Age Table, <http://optn.transplant.hrsa.gov/latestData/rptStrat.asp> (last visited Oct. 29, 2010).

³⁷ See *id.*

³⁸ Berger, *supra* note 7, at 69. Upon further research, statistics for SIDS infants and child abuse victims as organ donors is unavailable at this time.

³⁹ Child abuse victims are not usually young enough, and babies who die from SIDS are generally found dead due to a lack of oxygen, rendering organs useless. See *id.*

⁴⁰ See *id.*

that the baby died.”⁴¹ In the 60s and 70s, progress was made and parents were generally given contact with their baby to hold and feed them before they died.⁴² Additionally, the first organ transplant using an anencephalic infant’s organs occurred in the late 1960s when heart and kidney transplants were documented in a few American medical journals.⁴³

Following these mostly unsuccessful transplants, the medical profession regressed somewhat, turning back to a belief that anencephalic infants were “nature’s mistake and [parents should] get on with the business of having another child”⁴⁴ as soon as possible. The implications of this regression in the 1980s were somewhat unclear until the American Medical Association and the Council on Ethical and Judicial Affairs changed its position in reference to anencephalic infants in June of 1994, stating that “anencephalic [infants] have no consciousness and therefore do not have the rights of human beings.”⁴⁵ Severe backlash and an eventual suspension of this position followed the next December when most physicians, parents, clergymen and others expressed feelings that consciousness was still an unanswered question needing more review both legally and medically.⁴⁶

In an effort to review the issue, the Medical Task Force on Anencephaly documented forty-one anencephalic infant transplants in 1990.⁴⁷ Of those forty-one, only eleven kidney, one heart and no liver transplants were found to be successful.⁴⁸ Many reasons contributed to the failure of these transplants, including “rejection, thrombosis of graft vessels, and secondary complications not directly related to the graft.”⁴⁹ With the success rate so low, and lingering ethical as well as legal questions surrounding the transplants, use of anencephalic infants as a source for organs has virtually ceased altogether.⁵⁰ Some commentators have come to the decision that any further use of these

⁴¹ Harden, *supra* note 33, at 1286.

⁴² *See id.*

⁴³ Larry R. Churchill & Rosa Lynn B. Pinkus, *The Use of Anencephalic Organs: Historical and Ethical Dimensions*, 68 THE MILBANK QUARTERLY 147, 148 (1990).

⁴⁴ Harden, *supra* note 33, at 1286.

⁴⁵ Council on Ethical and Judicial Affairs, *The Use of Anencephalic Neonates as Organ Donors*, 273 JAMA 1614, 1615 (1995); *see also* Harden, *supra* note 33, at 1287.

⁴⁶ *See* Bard, *supra* note 2, at 62; *see also* Harden, *supra* note 33, at 1287.

⁴⁷ Stumpf, *supra* note 3, at 673.

⁴⁸ *See id.* The report also found the percentage of success was 30%, 0%, and 33%, respectively.

⁴⁹ *Id.*

⁵⁰ *See generally* Bard, *supra* note 2; Hanger, *supra* note 18; Berger, *supra* note 7.

infants' organs would necessitate a change in the laws regulating organ donation by abandoning the dead donor rule (requiring donors to be dead before they can donate non-regenerating organs) as it applies to anencephalic infants.⁵¹ Others believe a change in the law is not enough - society's moral opinion on the topic would need to change, either by accepting that anencephalic infants are not people or by deciding that anencephalic infants are never alive, even after birth.⁵²

So the question becomes: can we allow anencephalic infants to act as an organ source? Answering this question requires looking at the issues already raised: what is "personhood" and can anencephalic infants be considered legal persons with all the legal rights personhood entails? How do we define death and should that definition be changed to account for anencephalic infants? And finally, what are the parents' rights in all of this, considering these infants are minors and therefore cannot consent to organ donation themselves?

WHAT IS PERSONHOOD?

A discussion of personhood before anything else is required because if anencephalic infants are not persons, the discussion of whether they can be used as a source for organs becomes infinitely easier. Whether an anencephalic infant is considered a person has a large impact on their constitutional rights and whether their organs can be used for transplantation purposes. If they are considered non-persons, then the protections of the 14th Amendment would not apply and "surgeons could remove the newborns' organs for transplant purposes without criminal liability."⁵³ Therefore, it is important to make this determination.

What is personhood - Do anencephalic infants qualify as persons?

The Constitution has been interpreted "to require live birth as the accepted criterion for recognition as a 'person.'"⁵⁴ This means that a fetus not yet born, while given certain protections through various reg-

⁵¹ See Bard, *supra* note 2, at 92; Hanger, *supra* note 18, at 368; Harden, *supra* note 33, at 1310; Berger, *supra* note 7, at 84-85.

⁵² See Bard, *supra* note 2, at 92; see also Hanger, *supra* note 18, at 368.

⁵³ Paliokas, *supra* note 22, at 227. See also Churchill & Pinkus, *supra* note 43, at 160 ("If anencephalic infants are not 'persons,' but belong to some lesser category of beings, then the moral opprobrium and legal restraints from harming, wronging, killing, or using for other purposes are diminished.").

⁵⁴ Paliokas, *supra* note 22, at 226; see also *Roe v. Wade*, 410 U.S. 113 (1972).

ulations on abortion, is still not considered a person until birth.⁵⁵ Several characteristics have been used to distinguish personhood from other things: “biological life, genetic humanness, brain development, ability to feel pain, consciousness/sentience, ability to communicate, ability to form relationships, higher reasoning ability, and rationality.”⁵⁶ However, not all characteristics are required to be met to find personhood.⁵⁷

Anencephalic infants, like other individuals with mental or physical disabilities, are considered persons under the eyes of current law.⁵⁸ The most obvious evidence of their personhood is their birth. These infants are not embryos or fetuses, but living, breathing infants who are born in the same way as other infants. While some doubt exists that infants with anencephaly exhibit the characteristics of a person, it is documented that “these infants like other infants, sleep, eat, breathe, smile, and cry.”⁵⁹ Additionally, most infants with anencephaly have all the characteristics of biological life including a functioning brain stem; they are just missing a large portion of their brain.⁶⁰ They also have the same genetic structure as humans and despite their inability to meet the other required criterion set out by experts, it has never been established that anencephalic infants lack the protection of personhood.⁶¹ By meeting many of the required characteristics of personhood, anencephalic infants are entitled to all the rights and privileges that any other person possesses. As a result, their organs cannot be used for organ donation prior to a declaration of death under the current standard or a change in their current recognition as persons.

⁵⁵ See *Roe*, 410 U.S. at 158. Additionally, Louisiana actually recognizes ex utero embryos as “‘juridical persons,’ with rights to sue and liability to being sued.” See also Jessica Berg, *Of Elephants and Embryos: A Proposed Framework for Legal Personhood*, 59 HASTINGS L. REV. 369 (2007).

⁵⁶ Berg, *supra* note 55, at 375. It is, however, important to realize “that no single criterion can capture the concept of a person.” Jane English, *Abortion and the Concept of a Person*, 5 CAN. J. PHIL. 233, 234 (1975).

⁵⁷ See Berg, *supra* note 55, at 375.

⁵⁸ See *id.* at 378 (stating that while these infants may not be able to meet all the criterion listed, “[S]ociety has thus far been unwilling to deny even anencephalic infants the protections of personhood.”).

⁵⁹ Hanger, *supra* note 18, at 355.

⁶⁰ See *id.* at 354

⁶¹ See Berg, *supra* note 55, at 378 (noting that this protection may be attributable to the fact that “all human babies share the same external form and because there is a societal interest in encouraging specific caring behaviors towards all infants.”).

Implementing a New Standard – Why This is Untenable

To open the door for anencephalic infants to act as an organ source, some have suggested the solution is to deprive these infants of personhood.⁶² They believe that an infant with anencephaly “lacks the physical structure (forebrain) necessary for characteristic human activity,”⁶³ and that without the ability to think, remember things, or have conscious thoughts, they are essentially “brain absent” and therefore devoid of personhood.⁶⁴ Without personhood, theorists argue, the dead donor rule and other Constitutional protections should not apply to anencephalic infants,⁶⁵ thus allowing for the removal of their organs when needed.⁶⁶ While denying anencephalic infants personhood may appear to be an easy solution to the dilemma, it far from creates a resolution on the anencephalic organ donation issue.

Those who argue anencephalic infants lack personhood also rely on the fact that these infants lack a brain and thus are not alive—that a lack of life is evidence of a lack of personhood.⁶⁷ Using a similar line of reasoning, others propose allowing organs of anencephalic infants to be harvested and donated because the infants are born “brain-absent.”⁶⁸ These arguments are supported by the idea that “all rights enumerated in the Constitution and the Bill of Rights are predicated on consciousness . . . which becomes meaningless when consciousness can never exist, as in anencephalic infants.”⁶⁹ However, an infant “who is breathing, blinking, sucking, and moving cannot be considered ‘brainless’, for those activities are proof of a functioning brain.”⁷⁰ Thus, these arguments fail as valid reasons for denying personhood from anencephalic infants.⁷¹

⁶² See Khan & Lea, *supra* note 10, at 28; Scott, *supra* note 22, at 1550; Hanger, *supra* note 18, at 354.

⁶³ Paul Byrne, Joseph C. Evers & Richard G. Nilges, *Anencephaly—Organ Transplantation?*, 9 ISSUES L. & MED. 23, 33 (1993-1994).

⁶⁴ See Hanger, *supra* note 18, at 354; Khan & Lea, *supra* note 10, at 28; Scott, *supra* note 22, 1550.

⁶⁵ Khan & Lea, *supra* note 10, at 29.

⁶⁶ See *id.* at 28.

⁶⁷ See *id.* at 29.

⁶⁸ See Michael Harrison, *The Anencephalic Newborn as Organ Donor*, HASTINGS CENTER REP. Apr. at 21 (1986); see also Scott, *supra* note 22, at 1550.

⁶⁹ Ronald Cranford & David Smith, *Consciousness: The Most Critical Moral (Constitutional) Standard for Human Personhood*, 13 AM. J.L. & MED. 233, 247 (1987).

⁷⁰ Scott, *supra* note 22, at 1552.

⁷¹ More on whether the lack of a brain designates an anencephalic infant dead upon birth is discussed in the next section of this note.

Furthermore, courts across the country have defined personhood in various ways for various purposes, from deciding a fetus is not a person,⁷² to finding viability and thus personhood when there is “a realistic possibility of maintaining and nourishing a life outside the womb.”⁷³ Anencephalic infants are not fetuses because they are born and have a recorded birth certificate.⁷⁴ They also maintain themselves independent from medical assistance, even if it is only for a short time period.⁷⁵ Under these judicially-developed theories of personhood, infants born with anencephaly cannot logically be denied personhood because they meet the current requirements set out by the courts.

If the proposed reasoning for denying personhood to anencephalic infants is accepted, it becomes a slippery slope that can have many unforeseen effects down the road. Anencephalic infants develop, are born, and function in many ways the same as any other infant, except for the missing part of their brain.⁷⁶ Depriving them of personhood could be equated to depriving our senior citizens of personhood if they are diagnosed with Alzheimer’s or dementia. These seniors do not necessarily have the same mental capacity as others but are nonetheless considered “persons” in their own right. Accepting the theory that personhood is something anencephalic infants will never achieve would make it easy to take personhood away from other groups as well.⁷⁷

If we give these children a “new label” by calling them “products of conception incompatible with survivability [rather than “persons”], we no longer equate them with children.”⁷⁸ As so aptly put by scholar Joseph Harden, “a child with disabilities is no less of a person simply because she requires more care.”⁷⁹ It would be inhumane and would show an almost sick sense of desperation if society were to turn to depriving personhood from individuals in an effort to acquire their organs. There may be a great need for infant-sized organs, but is society ready to sacrifice its morals and values to satisfy this need? Probably

⁷² See *Roe v. Wade*, 410 U.S. 113, 157-58 (1973).

⁷³ *Planned Parenthood v. Casey*, 505 U.S. 833, 870 (1992); *In re T.A.C.P.*, 609 So. 2d 588, 595 (1992); *In re Baby K*, 16 F.3d 590 (4th Cir. 1994).

⁷⁴ See *In re T.A.C.P.*, 609 So. 2d at 590-91.

⁷⁵ See *Meinke*, *supra* note 8, at 2.

⁷⁶ See *In re T.A.C.P.*, 609 So. 2d at 590-91.

⁷⁷ See *Hanger*, *supra* note 18, at 359.

⁷⁸ *Harden*, *supra* note 33, at 1306.

⁷⁹ *Id.* at 1301.

not, due to the “well-entrenched value systems, including conservative approaches to major world religions.”⁸⁰

DEFINING DEATH

Having determined that anencephalic infants are people, entitled to Constitutional protections, the next logical analysis is to determine at what point these infants are dead. Not only is death a necessary component of organ donation, but it may also provide a way around the guaranteed Constitutional protections that personhood places with anencephalic infants, thus allowing for the use of their organs.

The Current Standard

With the development of successful organ donation procedures, regulations over the procedures as well as procurement and donation of organs began to develop on both the state and federal level, with much of the regulation surrounding the requirements for a person to be an organ donor.⁸¹ The Uniform Anatomical Gift Act of 1968 (UAGA), revised in both 1987 and 2006, was created to encourage organ donation and set out regulations for how donations would be made and received.⁸²

While the UAGA does not define death, it does require that organs not be taken for donation until a donor is declared dead.⁸³ This has been termed the “dead donor rule,”⁸⁴ first coined by John A. Robertson. However, there are a number of ways to define death and because many anencephalic infants still have a beating heart and

⁸⁰ Khan & Lea, *supra* note 10, at 30; Churchill & Pinkus, *supra* note 43, at 163 (“Efforts to redefine personhood, especially for reasons of exclusion, are self-reflexive: they say more about our basic humanity than about those we seek to redefine.”); *see also* Berger, *supra* note 7, at 85 (finding the power to deny personhood would jeopardize the “civil rights of all persons with disabilities”); Ian Anderson, *Surgeons Want the Organs of Babies ‘Born Brainless,’* 112 *NEW SCIENTIST* 20, 22 (1986) (noting that the use of these infants’ organs is “a legal gimmick aimed at circumventing the law.”); Harden, *supra* note 33, at 1310 (“Any utilitarian notion seeking to exploit a segment of the population for the ‘benefit’ of society would directly contradict our country’s moral and medical principles.”).

⁸¹ *See* Bard, *supra* note 2, at 56.

⁸² *See* Harrington, *supra* note 25, at 342; *see also* Paliokas, *supra* note 22, at 210.

⁸³ *See* Harrington, *supra* note 25, at 342. Additionally, the doctor declaring the death must be a different doctor than the one performing surgery and there is a release of liability for doctors who use good faith in transplanting organs but who inadvertently transplant organs of a technically living individual.

⁸⁴ John A. Robertson, *The Dead Donor Rule*, 29 *HASTINGS CENTER REPORT* 6 (1999).

functioning lungs, along with a functioning brain stem, they usually fail to meet the current brain death standard.⁸⁵ As a result, the definition of death is of paramount importance to this issue.

In defining death from a medical standpoint, most doctors and other healthcare professionals understand it to be something that occurs in stages rather than one point in time and these stages occur at different rates depending on the person.⁸⁶ To solve this dilemma, a committee from Harvard University established a criterion known as the “Harvard Criteria,” a precursor to what is now known as the Uniform Determination of Death Act (“UDDA”).⁸⁷ The Criteria establish a four-step analysis to establish whether brain death has occurred: “1) unresponsiveness and unresponsivity (to externally applied, intense stimuli); 2) no movement or breathing; 3) no reflexes; and 4) a flat or isoelectric electroencephalogram [EEG].”⁸⁸ Eventually, this criteria morphed into the UDDA, which declares death to have occurred when the patient has an “1) irreversible cessation of circulatory and respiratory functions, or 2) irreversible cessation of all functions of the entire brain, including the brain stem,” as determined “in accordance with accepted medical standards.”⁸⁹

While the standard of defining death under the UDDA has been proven applicable for adults, it is not applicable to infants in general,⁹⁰ or anencephalic infants in particular. First, most anencephalic infants do not meet any of the factors listed under the UDDA because they are responsive, they breathe on their own and can move around, and they show reflexes to different types of stimuli; also, testing them with an EEG machine is impossible because most of them only have a brain stem.⁹¹ Next, even if the established guidelines for brain death in children were to be adopted, anencephalic infants would still remain an untouchable source for organs because the standard only applies to

⁸⁵ See Harrington, *supra* note 25, at 342.

⁸⁶ See Paliokas, *supra* note 22, at 201-02. There is clinical death where respiration and circulation have stopped, brain death where the brain stops functioning, biological death where all systems of the brain and brain stem cease working, and finally cellular death when all tissue in the body has died.

⁸⁷ See Harden, *supra* note 33, at 1291; Paliokas, *supra* note 22, at 204.

⁸⁸ REPORT OF THE AD HOC COMMITTEE OF THE HARVARD MEDICAL SCHOOL TO EXPLAIN THE DEFINITION OF BRAIN DEATH, 205 JAMA. 337 (1968); Paliokas, *supra* note 22, at 204; Harden, *supra* note 33, at 1291-92.

⁸⁹ UNIF. DETERMINATION OF DEATH ACT 12A U.L.A. 781, §1 (2008).

⁹⁰ See Berger, *supra* note 7, at 75 (stating “[I]t is much more difficult to diagnose brain death in this group than in adults.”).

⁹¹ See Harden, *supra* note 33, at 1292.

infants seven days or older, an age not many anencephalic infants reach.⁹² A number of cases have come to the same determination, that anencephalic infants cannot be declared dead under the current UDDA standard, because their hearts are beating and their lungs are pumping without the help of medical intervention.⁹³

Another option for defining death is to turn to an analysis of the brain stem rather than the brain.⁹⁴ This type of analysis is relevant to anencephalic infants because their death is usually measured by the activity, or lack thereof, in their brain stem.⁹⁵ The “absence of brain stem function is determined by the lack of response of some brain stem reflexes,”⁹⁶ such as the corneal, cough, and gag reflexes. As with analysis under the UDDA standard, infants born with anencephaly often blink their eyes and have distinguishable gag reflexes and thus do not qualify as dead under this brain stem standard either.⁹⁷

It is clear that under the current standards for death, anencephalic infants cannot be declared dead until their heart stops beating and their lungs stop pumping or until they are declared brain dead. This creates a problem from an organ donation standpoint, because as discussed earlier, once organs have been deprived of blood and oxygen, they become virtually unusable as transplants for others.⁹⁸ Therefore, under the current standards, the use of anencephalic infants as a viable source for organs is prohibited. Any efforts to move in that direction will require a change in the law.

⁹² The Task Force for the Determination of Brain Death in Children recommends the condition of infants between seven days and two months be unchanged for forty-eight hours before they can be declared dead; however no recommendation was made for “seriously defective neonates under seven days of age.” Scott, *supra* note 22, at 1545-46; Bard, *supra* note 2, at 77. More specifics on the Task Force’s specific guidelines can be found in Task Force for the Determination of Brain Death in Children, *Guidelines for the Determination of Brain Death in Children*, 21 ANNALS OF NEUROLOGY 616 (1987).

⁹³ See *In re T.A.C.P.*, 609 So. 2d 588, 588 (1992); see also *In re Baby K*, 16 F.3d 590, 590 (4th Cir. 1994) (finding anencephalics are just as deserving of medical treatment as AIDS patients); see also Khan & Lea, *supra* note 10, at 29 (“In several instances, courts have made it clear that despite recognizing that anencephalic children do not possess consciousness, they do not view anencephalic infants as legally dead from the outset of their existence”).

⁹⁴ See James W. Walters & Stephen Ashwal, *Organ Prolongation in Anencephalic Infants: Ethical & Medical Issues*, 18 HASTINGS CENTER REP. 19, 25 (1988).

⁹⁵ See *id.*

⁹⁶ Byrne, Evers & Nilges, *supra* note 63, at 28.

⁹⁷ See Cranford & Smith, *supra* note 69.

⁹⁸ See Paliokas, *supra* note 22, at 197.

Implementing a New Standard - Why This is Untenable

It has been suggested that the solution to this dilemma of defining death for anencephalic infants is to change the UDDA in some way to include anencephalic infants.⁹⁹ This may involve declaring all infants born with anencephaly to be dead upon birth, or maintaining life artificially through respirators to sustain oxygen flow, thereby allowing for organ retrieval.¹⁰⁰ Changing the UDDA standard of death in this way may allow for anencephalic infants to be a source of organs for other infants, but this type of change has not generally been accepted.¹⁰¹ Many individuals believe that to depart from the current UDDA standard would be “a radical departure from the accepted social and medical understanding of what it means to be dead”¹⁰² and raises enormous concerns about the slippery slope such a change might create for other similarly handicapped infants.¹⁰³

For example, in Florida, the parents of an anencephalic newborn petitioned the court to declare their newborn baby dead for the purpose of organ donation.¹⁰⁴ To accomplish this, the parents proposed modifying the UDDA definition of death to allow for an automatic determination of death in anencephalic infants upon birth.¹⁰⁵ The court found “no basis to expand the common law to equate anencephaly with death,”¹⁰⁶ placing the foundation of its decision on medical statements that “so few organ transplants will be possible . . . as to render the enterprise questionable.”¹⁰⁷ The court also used studies indicating fewer anencephalic infants are actually born in addition to strong pressure coming from the 1981 presidential commission, urging “strict ad-

⁹⁹ See Meinke, *supra* note 8, at 3; see also Hanger, *supra* note 18, at 351-52.

¹⁰⁰ See Berger, *supra* note 7, at 78; see Scott, *supra* note 22, at 1548.

¹⁰¹ See Harden, *supra* note 33, at 1304; see also Scott, *supra* note 22, at 1553.

¹⁰² Scott, *supra* note 22, at 1552-53; see also Paliokas, *supra* note 22, at 235-37; see also Bard, *supra* note 2, at 79 (stating this type of change in the definition of death could include “other people without consciousness, most notably those in a permanent vegetative state . . . [and] could be expanded to include people who are conscious but have very short life expectancies, such as babies with fatal defects.”).

¹⁰³ See Scott, *supra* note 22, at 1553; see also Paliokas, *supra* note 22, at 235-37; see also Bard, *supra* note 2, at 79-80.

¹⁰⁴ See *In re T.A.C.P.*, 609 So. 2d 588, 589 (1992).

¹⁰⁵ See *id.*

¹⁰⁶ *Id.* at 595.

¹⁰⁷ *Id.* at 594.

herence to the Uniform Determination of Death Act's definition"¹⁰⁸ by courts.

Although it may seem easier to declare these infants dead when they are born, the struggle created by the UDDA's current definition of death is a purposefully placed "wedge"¹⁰⁹ that can ensure the protection of those who cannot speak for themselves and "to press for a . . . redefinition of death in order to . . . harvest organs, is only likely to lead to clinical confusion and public mistrust."¹¹⁰ Furthermore, declaring an entire category of children automatically dead is too risky "without identifying their condition with medical certainty."¹¹¹

Declaring anencephalic infants "dead on arrival" also raises an interesting issue of discrimination against those with disabilities. This issue was raised in the landmark *In re Baby K*¹¹² case in Virginia, where the court established that the hospital in question was required to treat Baby K, an anencephalic infant, because to refuse treatment would violate a host of federal laws, including the Rehabilitation Act and the Americans with Disabilities Act.¹¹³ Disability, whether physical or

¹⁰⁸ *Id.*; see also Berger, *supra* note 7, at 78 ("[C]ardiopulmonary support for the sole purpose of organ procurement is untenable if it causes extended survival and suffering in the infant."); see also Scott, *supra* note 22, at 1561 (describing the failed California Senate Bill 2018 in 1986, proposing to declare anencephalic infants dead and the failed New Jersey Bill No. 3367 that would have allowed parents to donate organs of their anencephalic infants before they were declared brain dead).

¹⁰⁹ See *In re T.A.C.P.*, 609 So. 2d at 594; see also Berger, *supra* note 7, at 78 ("[C]ardiopulmonary support for the sole purpose of organ procurement is untenable if it causes extended survival and suffering in the infant."); Scott, *supra* note 22, at 1561 (describing the failed California Senate Bill 2018 in 1986, proposing to declare anencephalic infants dead, and the failed New Jersey Bill No. 3367 that would have allowed parents to donate organs of their anencephalic infants before they were declared brain dead).

¹¹⁰ Churchill & Pinkus, *supra* note 43, at 159-160.

¹¹¹ Hanger, *supra* note 18, at 367; see also Bard, *supra* note 2, at 80; Khan & Lea, *supra* note 10, at 31 ("The slippery slope is real' and should not be discounted, as some physicians have in the past proposed transplants from infants with defects that fall short of the severity of anencephaly.") (quoting Beth Brandon, *Anencephalic Infants as Organ Donors: A Question of Life or Death*, 40 CASE W. L. REV. 781, 800-01 (1990)).

¹¹² *In re Baby K*, 16 F.3d 590, 590 (4th Cir. 1994).

¹¹³ See *id.* at 590-91. Section 504 of the Rehabilitation Act of 1973 states "[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 394 (1973) (codified as amended at 29 U.S.C. 794(a) (1994)). The Americans with Disabilities Act makes a similar statement, indicating no one can be discriminated against or prevented from en-

mental, is defined by the Federal Code of Regulations as “any . . . condition affecting one or more of the following body systems: neurological, musculoskeletal; special sense organs, respiratory,”¹¹⁴ etc., thereby including anencephalic infants under its umbrella.

Under the current law, anencephalic infants are born alive, like any other infant, and they are considered persons entitled to Constitutional protection.¹¹⁵ The only way around these protections is to change the current law to declare these infants “dead on arrival.” However, by allowing the automatic declaration of death in those infants born with anencephaly, there would be a violation of the regulations previously listed, just as the refusal of treatment for *Baby K* was found to have violated these regulations.¹¹⁶ A new definition would in essence separate those infants born with anencephaly from all other infants, whether they are born with or without other birth defects. This cannot be permitted in the face of American values of equality and protection of human life.

In addition to declaring anencephalic infants dead on arrival, some have suggested taking measures to extend the infant’s body, if not its “life.”¹¹⁷ These suggestions include using a ventilator to prolong cardiopulmonary function or cooling techniques to preserve organ viability.¹¹⁸ However, allowing an infant’s cardiopulmonary system to maintain its functioning simply for the purpose of having the organs remain viable is contrary to the idea that everyone has a right to a peaceful and humane death and would make these infants a means to an end—providing organs for other needy infants.¹¹⁹ Moreover, they have rarely provided viable organs because of misdiagnosis and suita-

joying things any other person enjoys. See Americans with Disabilities Act of 1990, Pub. L. No. 101-336, §303 (codified at 42 U.S.C. §12182 (1994)).

¹¹⁴ Harden, *supra* note 33, at 1298 (quoting 28 C.F.R. § 36.104 (1995)).

¹¹⁵ Hanger, *supra* note 18, at 355.

¹¹⁶ See *In re Baby K*, 16 F.3d 590, 592, n.2 (4th Cir. 1994).

¹¹⁷ Hanger, *supra* note 18, at 365; see also Scott, *supra* note 22, at 1536 (noting that cooling an infant’s temperature is sometimes done to ensure organ viability).

¹¹⁸ See Scott, *supra* note 22, at 1536.

¹¹⁹ See Khan & Lea, *supra* note 10, at 23 (citing Immanuel Kant’s Categorical Imperative, that “calls for humans to be treated as ends in themselves, and never solely as a means to an end.”); see also Paliokas, *supra* note 22, at 236 (stating that “[B]y taking organs from a non-brain-dead infant, society is saying, in effect, that the donee’s life has more value than the infant’s life being taken.”); Harden, *supra* note 33, at 1309 (“All humanity is degraded when any group of people is treated as a means to an end, no matter how seemingly justified that end may seem.”).

bility of the organs due to lack of oxygen, blood, and/or size.¹²⁰ This has deeper and more long-term implications than the easily seen benefit of additional organs for infants in need.

At the risk of going too far, think of the policies adopted by Nazi Germany, where they “sought to improve Germany by exterminating persons deemed . . . abhorrent or unworthy of life.”¹²¹ It is doubtful that those who propose to change the definition of death in regards to anencephalic infants are looking to improve society somehow by eliminating those infants the way the Nazis eliminated Jews and others. However, it is not the role of legal and medical professionals to “judge another human being’s worth,”¹²² which is what takes place when you value someone only for the organs they have rather than the person they are.

The chasm that exists between those who want to maintain the current definition of death under the UDDA and those who advocate for changing the standard or the conditions under which the standard is applied to anencephalic infants leads many commentators to believe that consensus on the issue is nowhere near attainable at this point.¹²³ Moreover, the idea of declaring infants who are living, breathing, and have a heartbeat dead when they clearly have very alive-like characteristics, “instills in the public a fear that other individuals very near death also will be declared dead.”¹²⁴ This fear is so great that changing the law through the legislative process seems beyond our reach at this point in time.¹²⁵ Death is “inevitable for all of us, including the baby with anencephaly [and] a prediction that death will occur soon is not the same as being already dead.”¹²⁶ Having analyzed the issue, it is clear that declaring anencephalic infants dead instantaneously upon their birth is completely untenable at this time.

¹²⁰ See Hanger, *supra* note 18, at 366-67 (finding “60% of anencephalic infants’ organs will be too small to be transplanted due to premature birth or complications”).

¹²¹ Harden, *supra* note 33, at 1301.

¹²² *Id.*

¹²³ See Khan & Lea, *supra* note 10, at 23 (“[T]he level of consensus necessary to change the law regarding organ donation by anencephalic infants seems unlikely to exist in the near future.”); see also Bard, *supra* note 2, at 94 (“[U]ntil there is a consensus that these standards should be changed, anencephalic infants cannot and should not be used as sources for donor organs.”).

¹²⁴ Hanger, *supra* note 18, at 356.

¹²⁵ See *id.* at 356-57.

¹²⁶ Byrne, Evers & Nilges, *supra* note 63, at 33.

PARENTAL RIGHTS

Finally, in addition to the difficulty in defining personhood and death, the rights of the parents of anencephalic infants are a vital part of this discussion. It is generally understood that parents have a fundamental right to the care, custody, and control of their children,¹²⁷ but the important issue is how far does this control extend? Is it an absolute power or something more limited? Under current laws, this is somewhat unclear.

Can Parents Decide to Donate their Child's Organs?

“After a period of infertility treatments, Mr. and Mrs. M learned that they were going to have triplets. Mrs. M, shortly thereafter, developed a fear that something was wrong with one of the babies whom she had named Avery. An ultrasound, at seventeen weeks, confirmed Mrs. M’s fear: Avery [one of the fetuses] was missing her upper skull. She had anencephaly.”¹²⁸ Before Baby Avery’s birth, the Ms were told that their baby’s life could mean something more through organ donation upon birth.¹²⁹ However, shortly before Avery’s birth and after the point where an abortion would have been an option, the Ms were told “Baby Avery could not be an organ donor,” despite being previously “led to believe [organ donation] was a possibility.”¹³⁰ This, unfortunately, is not an uncommon situation for parents of anencephalic infants. Most parents choose to abort upon diagnosis; nevertheless, some do choose to carry the baby to full term in hopes of donating its organs.¹³¹ Given the difficulties already addressed, the question at issue becomes whether parents should be allowed to make this kind of decision about their child or is it something better left to the medical and legal communities.

Under the UAGA, the donor or the donor’s next-of-kin must give informed consent for the donor’s organs to be removed and donated.¹³² In addition, for those individuals who are considered minors, parental consent is also required because the “custody, care and

¹²⁷ *Troxel v. Granville*, 530 U.S. 57, 66 (2000) (stating that parents have a fundamental right to make decisions concerning the care, custody, and control of their children).

¹²⁸ Bard, *supra* note 2, at 49.

¹²⁹ *Id.* at 51.

¹³⁰ *Id.*

¹³¹ Paliokas, *supra* note 22, at 216.

¹³² Hanger, *supra* note 18, at 357-58.

nurture of the child reside first in the parents.”¹³³ Finally, judicial consent is sometimes required in the case of a minor without a parental figure or those who are deemed incompetent to make their own medical decisions.¹³⁴ For children, the court has established “decisional responsibility [vests] in the parents . . . subject to review in exceptional cases by the State acting as *parens patriae*.”¹³⁵ This comes as a result of the Constitution’s protection of the right to privacy, including a parent’s right to make decisions about their child’s upbringing.¹³⁶ It is also important to understand this autonomy has its limits—parents cannot make a decision that is “clearly against the infant’s best interests.”¹³⁷ While privacy rights of the parents are respected,¹³⁸ it is usually the child’s best interest that is ultimately held in higher regard.¹³⁹

The Debate

Parental rights in relation to anencephalic infants are different than the first two issues addressed in that there is no status quo vs. new standard position. “The need to find meaning in the life of anencephalic babies makes organ donation by anencephalic infants a bitterly difficult problem.”¹⁴⁰ The courts are not generally in agreement on this issue and decisions run the gamut from analysis of the

¹³³ Paliokas, *supra* note 22, at 211 (citing *Stanley v. Illinois*, 405 U.S. 645, 651 (1972)).

¹³⁴ *See id.* at 213-24. The Court uses one of two standards: the “best interests” standard looks at what is in the best interests of the patient and acts with those interests in mind and the “substituted judgment standard” involves the court substituting its own judgment and then acting as it thinks the individual would in a similar situation. The latter is usually used only in medical emergencies where “a high probability of success exists along with a clear duty to act, and the best interest of the donor . . . require it.” *Id.* at 213-215.

¹³⁵ *Bowen v. American Hospital Ass’n*, 476 U.S. 610, 627 (1986).

¹³⁶ *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925); Paliokas, *supra* note 22, at 211.

¹³⁷ Paliokas, *supra* note 22, at 212 (quoting PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *Deciding to Forgo Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*, ch. 2, at 6 (1983)).

¹³⁸ *See Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941) (finding for a mother who did not give consent for a skin graft on her son for the benefit of his cousin); *see also Zaman v. Schultz*, 19 Pa. D. & C. 309, 313 (1932) (finding for the parents when blood was taken from minor daughter for the benefit of someone else without parent’s consent).

¹³⁹ *See In re Eichner*, 73 A.D.2d 431, 477 (N.Y. App. Div. 1980), *modified*, 52 N.Y.2d 33 (1981) (stating that a guardian *ad litem* appointment for minor children “assure[s] that the interest of the patient are indeed protected by a neutral and detached party wholly free of self-interest” rather than a parent whose interests may clash with that of the child); *see also* Paliokas, *supra* note 22, at 212

¹⁴⁰ Bard, *supra* note 2, at 92.

child's welfare in light of treatment¹⁴¹ to the assertion that the privacy rights of the parents reign supreme.¹⁴² The ultimate analysis the court comes down to is balancing "the bodily integrity of one newborn against the social value of saving another newborn's life."¹⁴³

Those who favor parental privacy rights on this issue and support allowing parents to donate a child's organs when he or she is diagnosed with anencephaly argue the altruism of the parents, "the psychological benefits parents receive by lessening their tragedy, and the benefits to society"¹⁴⁴ all justify giving parents decisional autonomy over their anencephalic infant's organs. It is argued that by allowing parents to make this decision, it is ultimately benefiting more people than otherwise would be helped if parents were required to abide by current dead donor laws.¹⁴⁵ However, these arguments fail to ask at what cost are privacy and benefit being acquired. After all, "not all altruistic behavior is good. Altruism describes only what motivates an action, not its style, form, content, or outcomes."¹⁴⁶

The argument against allowing parents to donate their anencephalic infant's organs tends to stand on the value of life, arguing that to allow parents the power to determine the life or death of their child by allowing them to donate their infant's organs debases the "sanctity of life . . . and equal value of every life."¹⁴⁷ Placing the parent's desires and/or needs above those of the infant who cannot speak for him or herself ignores the best interest of the child in favor of the best interest of either the parents or the infant receiving the organs.¹⁴⁸ This could easily spiral downward into that slippery slope of disrespect of other similarly disabled individuals.¹⁴⁹

¹⁴¹ See, e.g., *In re Phillip B.*, 92 Cal. App. 3d 796 (1979), cert. denied, *Bothman v. B.*, 445 U.S. 949 (1980).

¹⁴² See, e.g., *In re Guardianship of Barry*, 445 So.2d 365 (Fla. Dist. Ct. App. 1984).

¹⁴³ Paliokas, *supra* note 22, at 218, 234 ("The anencephalic newborn's parents embody this rights conflict in that, while theoretically exercising the privacy right of their infant, they also exercise the right to life of the donee by choosing to donate their newborn's organs.").

¹⁴⁴ *Id.* at 235.

¹⁴⁵ *Id.* at 234-235.

¹⁴⁶ Churchill & Pinkus, *supra* note 43, at 156.

¹⁴⁷ Paliokas, *supra* note 22, at 235.

¹⁴⁸ See *id.* at 236 ("Opponents argue that any other approach does not focus on the best interests of the anencephalic newborn and could become a justification for taking organs from comatose, mentally deficient or other handicapped individuals who become a burden to society"); see also Churchill & Pinkus, *supra* note 43, at 155-56.

¹⁴⁹ See Paliokas, *supra* note 22, at 236-37; see also Churchill & Pinkus, *supra* note 43, at 155-56.

It can also shift the focus of the discussion from that of the infant and its care to the parents and their recovery. It is important 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.”¹⁵⁰ It is the rights of the infant as an individual that is at the center of this dilemma and allowing the parents to become “patients” of a sort, needing to use the donation of their child’s organs as a “form of therapy,”¹⁵¹ degrades the infant’s rights and protections as a living human being.¹⁵² It is not that the parents would necessarily make a decision that is not in the best interest of their child, but parents in this situation are put in a very difficult situation by having to balance their emotional response to the situation with what is best for their child. By appointing the court or a guardian *ad litem* to make decisions about the infant, it can be assured the interests of the child are put first, rather than the emotions and interests of the parent.

While it may be easy to see the benefit of enabling parents to make this decision rather than leaving the decision to the courts or a guardian *ad litem*, a higher order of rights for the infant and its life must override the privacy concerns of the parents. It would be different if the infant were already declared dead because it has been established that parents have an absolute right over the “dispos[al] of their child’s body;”¹⁵³ however, that is not the case here and is not possible, given the previous discussion on personhood and the definition of death. Doctors cannot violate laws and regulations simply because a parent wants a certain action taken, and by allowing parents to make the decision to donate their infant’s organs, violations would occur. Until consensus between society, the legal community, and the medical field develops, this should be the guiding law on the issue of parental rights.

WHERE DO WE GO FROM HERE?

It is obvious from the literature, case law, and numerous medical studies on the topic, that the question of whether anencephalic infants should be used as an organ source is still an ongoing issue. The current standards do not enable these infants to act as a source for organs because they do not meet the requirements to be found dead under

¹⁵⁰ Churchill & Pinkus, *supra* note 43, at 156.

¹⁵¹ *Id.*

¹⁵² *See id.*

¹⁵³ Bard, *supra* note 2, at 75.

the UDDA, they are in fact people with the right to life, and as a result of that right should be guaranteed protection, even from their parents when necessary. Numerous suggestions have been made to enable the organs of these infants to be used for others, from maintaining the infants on life support until death under the current standard occurs,¹⁵⁴ to cooling the infant's body to preserve the organs for harvesting,¹⁵⁵ to declaring the infant dead upon birth, having never acquired the rights that come with personhood.¹⁵⁶ However, just because an anencephalic infant will never function completely like other infants, "does not mean that the child is not, nor ever has been alive."¹⁵⁷

It is obvious that one of the biggest "barriers to anencephalic organ donation [is] based on what we as society are willing to call life and death"¹⁵⁸ and much has been said about that issue. However, until the division between life and death for anencephalic infants can be defined more clearly and with unanimity, it will remain a barrier to any efforts to change the current prohibition on anencephalic organ donation.¹⁵⁹

¹⁵⁴ See *id.* at 93; see also Scott, *supra* note 22, at 1548-50 (discussing the Loma Linda Protocol, which implemented life support to preserve organs of anencephalic infants).

¹⁵⁵ See Scott, *supra* note 22, at 1546-47.

¹⁵⁶ See Churchill & Pinkus, *supra* note 43, at 160-61.

¹⁵⁷ Bard, *supra* note 2, at 94.

¹⁵⁸ *Id.* at 92.

¹⁵⁹ See *id.*