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BABY DOE AND BEYOND: EXAMINING THE PRACTICAL AND PHILOSOPHICAL INFLUENCES IMPACTING MEDICAL DECISION-MAKING ON BEHALF OF marginally-VIABLE NEWBORNS

Craig A. Conway*

ABSTRACT

Infants born at twenty-seven weeks of gestation or less, or weighing less than 1000 grams, are considered to be extremely premature. These newborns teeter on the cusp of viability; it is only with aggressive medical intervention applied to virtually every bodily system that they have any chance of survival. If these marginally-viable newborns do, in fact, survive, they likely will experience a lifetime of severe physical, mental, and emotional handicaps—often as a direct result of the medical treatment they received. Consequently, this population represents one of the most contested treatment groups in medicine.

Advances in technology and medical education in the past century have allowed doctors to save some of these extremely premature newborns who previously would have most certainly died. However, the philosophical, ethical, and legal concerns raised by attempting to preserve these infants are being weighed by an increasing number of decision makers. Whereas, prior to the 1970s, decisions regarding the infant's treatment plan were primarily in the hands of the parents and physicians—that is no longer the case. What was once a private decision made by these grief-stricken parents with the advice of their physicians has since become a matter for the public domain. These fragile infant's outcomes are now being debated by parents,

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physicians, hospital administrators and bioethics committees, legislators, courts, media outlets, and the general public. The current situation is less problematic when the decision-making agents are in agreement regarding the infant's course of treatment. However, when disagreements arise, a once private heartbreak can now become a public controversy that lacks a single, agreed-upon agent for making the life and death care choices in the best interests of the newborn. Instead, a seemingly moral, ethical, and legal tug-of-war between the parties can erupt, each differently valuing the medical condition and care of the barely viable neonate whose potential quality of life is unknown.

After introducing the multiple actors and variables that lead to the emergence of conflict in medical decision making on behalf of a marginally viable infant, this Article details the practical criteria physicians use when determining whether aggressive medical treatment should be initiated or when palliative care should be provided to an extremely premature infant. The Article then discusses the sometimes difficult process of determining a medical treatment plan made in the "best interests" of the infant. The Article then explores the value system of vitalism often possessed by parents or others adamantly expressing that their child's life should be preserved at all costs, and often in spite of the pain and suffering endured by the newborn; such a belief system often leads to conflict in medical decision making and may ultimately lead to litigation. Though they are not cases of extreme prematurity, the medical and legal cases of Sun Hudson and Emilio Gonzales are representative of such resulting litigation. The Article then examines the chronological history, evolution of, and subsequent impact of the Baby Doe regulations initiated by the Reagan Administration. Next, the Article examines the medical and legal case of Sidney Miller which best represents conflict resulting from the convergence of the multiple variables discussed. The Article then examines the most recent legislative initiative to inject a philosophical preference for the sanctity of life into medical decision making via the Born-Alive Infants Protection Act of 2002. The Article then provides

recommendations to reduce or remove parent-physician conflict and concludes with an argument for consistent assessment of the infant, care and counseling to be provided to families, and collaborative decision making to determine a medical course of action that is in the best interests of the infant.

INTRODUCTION

Set off in a small meeting room just outside the neonatal intensive care unit (NICU) at a nearby hospital, the parents of an infant born at the edge of viability meet with the attending neonatologist to discuss their newborn's grim prognosis. Sitting on the blue vinyl couch tucked in the corner of the sterile beige room, the parents look to the physician for answers in a seemingly hopeless situation. For a moment, the whirring of the overhead ceiling fan is the only sound heard. This was not where the parents envisioned themselves eventually sitting when they first learned they were going to have a child. Then the neonatologist begins to lay out the cold, hard facts about their child's medical condition. Born at twenty-four weeks of gestation, the newborn is sixteen weeks premature of the forty weeks required of a full-term pregnancy. Weighing just over two pounds, the infant could fit into the palm of an adult hand. Every organ and system in the fragile infant's body is underdeveloped and struggling to function. The child is unable to breathe without assistance from a respirator and recently developed an infection that appears to be getting worse. There are small, thin lines of varying colors inserted at various locations on the infant's body, delivering antibiotics, steroids, nutrition, and other medicines to ensure the infant's survival. Beeping and buzzing machines loom nearby to inform medical staff of the infant's heart rate, breathing rate, and blood pressure. Looking at the newborn in its current state is not easy. Its skin is nearly translucent and wrinkled and purple veins are easily visible running throughout its body. It appears to be struggling, but it is difficult to be sure. Prolonging its life through medical means may eventually only cause it pain and suffering. The physician informs the parents that even if

their child survives, a lifetime of disabilities likely awaits including blindness, seizures, cerebral palsy, and mental retardation. There are no guarantees the neonatologist can provide. Then the physician asks the question: "What would you like us to do? Do you want us to continue doing everything we can to save your child? Or do you want us to provide comfort care so that the child may peacefully die?"

This Article addresses medical decision-making made on behalf of the most vulnerable of infants, those born alive but who without receiving aggressive medical intervention would most certainly die. They are typically born at twenty-seven weeks of gestation or less and teeter on the cusp of viability. They are the borderline cases physicians confront frequently; unable to sustain life on their own, these newborns' futures are often in the hands of neonatologists and other pediatric specialists. Given the technological advances and medical knowledge at their disposal, neonatologists often must decide not if they can, but if they *should* intervene to force life upon an infant. Parents, lacking the medical expertise of the physician, make extremely difficult decisions that pursue life or permit death for their child. To choose life with resulting severe handicap takes a profoundly deep emotional, psychological, and financial toll on the parents and family. To choose death brings similar grief and sometimes private regret that the parents should have chosen differently. For nearly fifty years, NICUs have been the locus for this debate.

Prior to the 1970s, decisions regarding the child's treatment plan were primarily in the hands of the parents with physician consultation; that is no longer the case. Parental autonomy in making medical decisions on behalf of a child has been constrained in the past thirty years. Today, the philosophical and practical concerns raised by attempting to preserve these infants are being weighed by an increasing number of decision makers including multiple physicians, hospital administrators and bioethics committees, legislators, courts, media outlets, and the general public. What was once a private decision made by these grief-stricken parents, has since become a matter for the public domain. The current situation is

relatively unproblematic when the decision-making actors are in agreement regarding the infant's course of treatment. However, when disagreements arise, a once private heartbreak can now become a public debate that lacks a single, agreed-upon agent for making the life and death care choices in the best interests of the newborn.

This Article begins by briefly exploring the historical restriction on parental autonomy in making private medical treatment decisions on behalf of an imperiled newborn due, in part, to an increasing number of outside public influences. Then, after examining the practical, medical criteria physicians use when determining whether aggressive medical treatment or only palliative care should be provided to an extremely premature infant, the Article explores the Best Interests Standard, commonly used by physicians to guide medical treatment decisions on behalf of extremely premature infants. Next, the Article examines the philosophical value system of vitalism often held by parents and others, which holds that a child's life is to be preserved at all costs and often regardless of the pain and suffering endured by the infant. Vitalist beliefs of the parents often conflict with practical medical treatment decisions and ultimately may lead to litigation in an attempt to resolve the disputes. The Article examines the legal cases of Sun Hudson and Emilio Gonzales as representative of such litigation. The Article then provides a chronological history of the largely philosophical attempt by the Reagan Administration to legislatively remove parental autonomy in making medical treatment decisions on behalf of disabled infants through the enactment of the federal Baby Doe rules and their resulting impact on modern normative neonatal practice. As a premier example of the foregoing actors and variables in conflict, the Article next examines the medical and legal case of Sidney Miller—born extremely premature, and subsequently severely disabled, her parents' decisions to forgo resuscitation at birth were ignored by a health-care facility. The Article then provides recommendations for formulating medical treatment guidelines to reduce or remove parent-physician conflict and concludes with an argument for consistent assessment and reassessment of the infant, care and counseling to be provided to

parents and families, and collaborative decision making between physicians and parents to determine a medical course of action in the best interests of the infant.

I. A BRIEF HISTORY OF THE EROSION OF PARENTAL AUTONOMY AND THE EMERGENCE OF PUBLIC INFLUENCE IN MEDICAL DECISION MAKING FOR marginally-Viable newborns

United States legal tradition accords parents with presumptive authority to make decisions on behalf of a child based on the assumption that the parents will act in the child's best interests.¹ This authority extended to a parental right to direct the health-care decisions made on behalf of a child.² However, when forced to make difficult choices that mean the life or death of a child, parents often tend to be troubled by the awesomeness of the decision. Their anxiety does not stem solely from a desire to make the "right" decision; it is also generated by the input and opinions of treating physicians in whom parents place a great deal of trust to provide accurate medical information and to make realistic prognostic recommendations. Physicians, in turn, are often influenced by competing interests in the NICU, namely applying appropriate medical standards of care, considering input from and opinions of other physicians and medical staff, complying with hospital administration policies, following recommendations of bioethics committees, and adhering to state and federal law. Although a physician's priority is to his or her patient,

1. See, e.g., *Meyer v. Nebraska*, 262 U.S. 390, 399–400 (1923) (establishing a constitutional right of parental autonomy to direct the education of their children as rooted in the Fourteenth Amendment); *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 534–35 (1924) (relying on *Meyer* to further ground and guarantee parental rights); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (stating that "the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder").

2. See Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 5–6 (2000); see also *Parham v. J.R.*, 442 U.S. 584, 602 (1979) ("[N]atural bonds of affection lead parents to act in the best interests of their children."); Shellie K. Park, *Severing the Bond of Life: When Conflicts of Interest Fail to Recognize the Value of Two Lives*, 25 U. HAW. L. REV. 157, 167–68 (2002).

the rank order of other interests and their possible influence on appropriate standards of care may affect physicians differently.

To complicate matters further, parental autonomy to make medical treatment determinations on behalf of a child, in concert with physician consultation, has been limited in the past thirty years by federal legislative initiatives based on the philosophical ideals of protecting all life—regardless of its quality.³ Accordingly, these federal laws have had the effect of not only limiting or denying parents the freedom to decide what is morally and medically proper in the best interests of a child, but has increasingly thrust these once-private matters into the public domain for discussion. When challenged, the courts have frequently (but not consistently) struck down the laws and sided with parents as the proper decision makers of their own child's future.⁴

What has developed is a seeming moral, ethical, and legal tug-of-war between parent and physician and between legislative and judicial actors, each actor differently weighing practical and philosophical influences in how to make difficult decisions on behalf of an extremely premature infant whose future quality of life is yet unknown. The result is confusion and a lack of consensus as to who has the final say in making medical decisions on behalf of an imperiled infant.

This section of the Article provides a brief historical account of the erosion of parental authority to make medical treatment decisions for a marginally-viable or disabled infant leading to federal legislative oversight attempting to philosophically preserve the sanctity of each individual infant's life.

3. See discussion *infra* Parts V, VII.

4. See *Parham*, 442 U.S. at 602; *Bowen v. Am. Hosp. Ass'n.*, 476 U.S. 610 (1986); *In re Infant Doe*, No. GU8204-004A (Monroe County Cir., Ind. Apr. 12, 1982) (deferring to parental decision to withhold treatment for a disabled newborn), *cert. denied*, 464 U.S. 961 (1983).

A. *The Erosion of Parental Autonomy*

Before 1970, questioning a parent's decision to withhold life-sustaining treatment from an extremely premature infant was rarely done by physicians.⁵ At the same time, noted physicians published articles in major medical journals about the practice of withholding life-saving medical treatment from certain disabled infants.⁶

In the social turmoil surrounding the early 1970s, including the Vietnam War, the abortion debate, and the resignation of a president, conservative fundamentalists and evangelicals, among others, became increasingly disturbed by liberalizing trends in the United States.⁷ In their opinion, "the legalization of abortion, the sexual revolution, and the gay rights movement," threatened traditional roles and was believed to be an indication that society was breaking down.⁸ These groups pushed back against those advocating for a woman's right to choose and touted homosexuality as a sin.⁹ In the midst of the abortion debate, a debate surrounding the value of life, the sanctity of life, and quality of life shifted to the newborn delivery room.

In 1973, neonatologists Raymond S. Duff and A.G.M. Campbell published a then-controversial article in the *New England Journal of Medicine* about withholding treatment to marginally-viable and defective newborns.¹⁰ Writing about their experiences, Duff and Campbell reported that fourteen percent (43 out of 299) of the deaths in the special care nursery of the Yale-New Haven Hospital from January 1, 1970 through June 30, 1972 were "associated with discontinuance or withdrawal of treatment."¹¹ All of the infants had some form of severe impairment that, in the judgment of the parents

5. See John A. Robertson, *Extreme Prematurity and Parental Rights After Baby Doe*, HASTINGS CENTER REP., Jul./Aug. 2004, at 32.

6. *Id.*

7. See Robert D. Woodberry & Christian S. Smith, *Fundamentalism et al: Conservative Protestants in America*, 24 ANN. REV. SOC. 25, 44 (1998).

8. *Id.*

9. See *id.*

10. Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (Oct. 25, 1973).

11. *Id.*

and physicians, made their prognosis for a meaningful life extremely poor or hopeless.¹² It was argued by the authors that parents must accept and be granted the responsibility to make treatment decisions on behalf of an infant. They wrote:

We believe the burden of decision-making must be borne by families and their professional advisors because they are most familiar with the respective situations. Since families primarily live with and are most affected by the decisions, it therefore appears that society and the health professions should provide only general guidelines for decision making. Moreover, since variations between situations are so great, and the situations themselves so complex, it follows that much latitude in decision making should be expected and tolerated.¹³

This viewpoint expressed by Duff and Campbell may, in fact, be the dominant approach utilized in modern neonatology.¹⁴ However, other practical factors and philosophical influences have since been added to the discussion. In direct response to Duff and Campbell's article, John Robertson and Norman Frost published an article in 1976 advocating the largely philosophical view that a newborn, regardless of how badly compromised he or she may be, has the right to life.¹⁵ In their opinion, parental autonomy in concert with guidance from physicians in making treatment decisions on behalf of disabled infants went too far.¹⁶ They emphasized a need for a set of authoritative guidelines to guide decision-making to prevent mistakes

12. *Id.*

13. *Id.* at 894.

14. See generally Joseph W. Kaempf et al., *Medical Staff Guidelines for Periviability Pregnancy Counseling and Medical Treatment of Extremely Premature Infants*, 117 PEDIATRICS 22, 23 (2006); Am. Acad. of Pediatrics Neonatal Resuscitation Prog. Steering Comm., *Born-Alive Infants Protection Act of 2001*, Public Law No. 107-207, 111 PEDIATRICS 680 (2003); Hugh MacDonald & The Comm. on Fetus and Newborn, *Perinatal Care at the Threshold of Viability*, 110 PEDIATRICS 1024 (2002); William Oh et al., *Perinatal Care at the Threshold of Viability*, 96 PEDIATRICS 974 (1995).

15. See John A. Robertson & Norman Frost, *Passive Euthanasia of Defective Infants: Legal Implications*, 88 PEDIATRICS 883 (1976); see also John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975).

16. Robertson & Frost, *supra* note 15, at 887.

or abuses of power.¹⁷ As a result of these publications and accompanying discussion, the once very private meeting in a small NICU meeting room between parents and a physician regarding the medical treatment plan of a barely viable infant was increasingly entering the public domain.

B. A Federal Push to Preserve the Sanctity of Life

In 1982, the death of a severely handicapped child with Down syndrome born six days earlier in Bloomington, Indiana, started a firestorm of national debate and discussion regarding treatment of extremely premature and disabled infants.¹⁸ Indiana courts approved the decision of Baby Doe's parents to forgo surgery to correct a tracheoesophageal fistula¹⁹ and to withhold food and other nutrition, effectively allowing the baby to die.²⁰

Outraged by the court's decision, President Ronald Reagan used the case of Baby Doe as a call for his administration to employ Section 504 of the Rehabilitation Act of 1973 to prevent future denials of treatment to disabled newborns. Coined "the Baby Doe Rules" (or Regulations), Reagan's attempt to sway medical standards of care was rebuffed by the United States Supreme Court in *Bowen v. American Hospital Association, et al.*,²¹ which held, among other things, that no evidence existed to indicate that a "discriminatory withholding of medical care" was used in violation of section 504 and further, that the section did not authorize the Secretary of Health and Human Services to "give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions" regarding handicapped or disabled children.²² Some commentators went a step further, opining that the Court's decision

17. *Id.*

18. See discussion *infra* Part V.

19. A condition where the upper part of the esophagus is not connected to the lower part preventing the intake of food.

20. See Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J. L. & GENDER 425, 429 (2006).

21. 476 U.S. 610 (1986).

22. *Id.* at 611.

held that the rules interfered with parental rights to decide what was in their infant's best interest, thwarted individualized choices, and were naïve about proper medical decision-making.²³ Though this first version of the Baby Doe Rules was struck down by the Court, President Reagan did not give up.

After the Court's decision in *Bowen*, Reagan again attempted to force physicians and health-care facilities to preserve the sanctity of life when making medical treatment decisions by urging Congress to amend the Child Abuse Prevention and Treatment Act (CAPTA).²⁴ As passed, these federal funding regulations require all extremely ill, premature infants less than one year of age to receive maximal treatment unless any of three narrow exceptions is met.²⁵ If a health-care facility violated the terms of CAPTA, it theoretically could lose valuable federal monetary grants.²⁶

Neonatologists and other physicians responded that the rules were unnecessary to protect the rights of marginally-viable newborns and failed to offer adequate consideration of the infant's physical condition, ignored the rights of parents, and negated the Best Interests Standard as a guide to make medical determinations.²⁷ The rules have generated confusion among physicians about what practical and philosophical factors they must consider when determining a proper medical course of action.²⁸

23. *Id.*; see also Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 191 (2007).

24. 42 U.S.C. §§ 5101–5107, 5118 (2006).

25. See Kopelman, *supra* note 23, at 191. The three exceptions to providing maximum treatment are: (1) if the infant is chronically and irreversibly comatose; (2) treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (3) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. *Id.*

26. *Id.*

27. See Loretta M. Kopelman, Thomas G. Irons & Arthur E. Kopelman, *Neonatologists Judge the 'Baby Doe' Regulations*, 318 NEW ENG. J. MED. 677, 677 (1988); Loretta M. Kopelman, Thomas G. Irons & Arthur E. Kopelman, *Neonatologists, Pediatricians and the Supreme Court Criticize the 'Baby Doe' Regulations*, in COMPELLED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS 237 (Arthur L. Caplan, Robert H. Blank, Janna C. Merrick, eds. 1992).

28. See sources cited *supra* note 27.

As recently as 2002, Congress yet again enacted legislation that effectively interferes with parental autonomy to make medical decisions on behalf of a marginally-viable newborn. The Born-Alive Infants Protection Act of 2002 (BAIPA)²⁹ was passed “to repudiate the flawed notion that a child’s entitlement to the protections of the law is dependent upon whether the child’s mother or others want him or her.”³⁰ Initially understood by legislators and the medical community to be an anti-abortion law, BAIPA eventually found its way into the newborn delivery room. Under the terms of the Act, resuscitation and other life-saving measures must be initiated on an infant “born alive” if a heartbeat is detected or it otherwise shows signs of life.³¹ Thus, an extremely premature infant born with no hopes of long-term viability must, according to BAIPA, be administered maximal life-saving medical treatment, likely resulting in a bad death or a severely disabled life.

C. The Role of Vitalism in Making Difficult Life or Death Decisions

The surge of vitalism, the belief that every individual life should be preserved at all costs regardless of quality-of-life concerns, has only largely permeated our society in the past quarter of a century. Anthropologist Emily Martin contends that our culture underwent a shift in the last thirty years from a focus on a “societal-good” (efforts to benefit society as a whole) to the intensification of individualization, as best seen from President Reagan’s commitment to protect the rights of each individual infant.³² This cultural shift has, in part, led to an increased desire by patients and surrogate decision makers to maximize health-care resources for an individual—often at the expense of others who may benefit equally if not more from their use. Parents expressing a vitalist belief want to maximize those resources on a dying infant or an infant that may have a minimal or

29. Born-Alive Infants Protection Act of 2002, Pub. L. No. 107-207, 116 Stat. 926 (2002).

30. H.R. REP. NO. 107-186, at 3 (2001).

31. *Id.* at 20.

32. Suzanne R. Kirschner, *From Flexible Bodies to Fluid Minds: An Interview with Emily Martin*, 27 ETHOS 247, 266-67 (1999).

even non-existent quality of life. In those instances, parents fervently believe that life, in and of itself, is a good to be cherished and upheld—even if the medical resources utilized are inflicting pain and suffering on the infant. Parents attempting to preserve and promote the sanctity of life ethic often clash with physicians or other health-care providers, advocating practical medical concerns in the best interests of the newborn. Such disagreements often lead to litigation.³³

D. A Personal Note

From personal experience, having a child in a hospital NICU is an anxiety-filled experience. As a new parent, I watched my son struggle to breathe his first breaths. He was not born prematurely, yet he immediately developed a life-threatening condition.³⁴ After a quick discussion of his condition and needed treatment with physicians and nursing staff, he was then whisked away from my wife and me by nursing staff before we had an opportunity to hold him and welcome into the world. Placed in an incubator to receive warmth and much needed oxygen, it would be over a week before my wife and I would be able to touch him.

The medical condition that would have surely ended my son's life thirty years ago, as it did my brother's when he was about four days old, was treated by excellent physicians and medical staff taking advantage of the latest technology and procedures. The physicians were kind, informative, and reassuring. The treatment provided

33. See discussion *infra* Part III.C–D.

34. The author's son was born Dec. 31, 2005, just over thirty-nine weeks' gestation and suffering from respiratory distress syndrome (RDS) and persistent pulmonary hypertension (PPHT). When an infant suffers from RDS, his or her lungs are not developed enough to produce surfactant, a liquid that coats the inside of the lungs and keeps them open so that the baby can breathe in air. Without surfactant, the lungs collapse and the baby has to work hard to breathe on his or her own. The extra work causes persistent pulmonary hypertension where the blood vessels in the lungs constrict, and as a result there is insufficient blood flow to the lungs and not enough oxygen reaches the blood. The author's son was admitted to the NICU at Univ. Ala.-Birmingham (UAB) and received treatment spanning nearly ten days. His son will turn three this December and is completely healthy. The author would like to thank everyone in the UAB NICU who devotes his or her time to treating, saving, and sometimes saying goodbye to newborns.

allowed him to be placed on his own meaningful life path. But during his nearly two-week stay in the NICU, my son was surrounded by much more fragile infants whose futures were less hopeful. My wife and I had to make difficult decisions regarding my son's treatment in that small meeting room just outside of the NICU, but the decisions we made pale in comparison to the agonizing decisions made by parents, sitting on that blue vinyl couch, presented with a grim outlook of their barely viable infant's future. Their once private matter has culminated into a public discussion and debate regarding whether their child should live a life, possibly lacking truly meaningful relationships and experiences, or whether the child should die with dignity and in peace. Physicians are on the front lines, treating the expectant mother and subsequently delivered newborn, making the medical determinations and recommendations that often begin the decision-making process.

II. PHYSICIANS' TREATMENT OF THE INFANT'S PHYSICAL CONDITION

Not all extremely premature infants are born alike. This oversimplified statement may appear obvious at first blush, but in the context of survivability or the likelihood of having long-term debilitating disabilities, it is precisely the vital differences in the newborn's weeks of gestation, weight, gender, and other factors that are crucial, practical variables physicians must weigh when making medical treatment decisions and presenting treatment options to parents. But even the wealth of information and experience gained in the past century by neonatologists in treating fragile newborns has created unanswerable questions.

Newborn medicine in the twentieth century produced a plethora of medical curiosity and technological advances.³⁵ Today, neonatology has evolved to where many of the same treatments that are successfully provided to older children and adults are similarly

35. See EARL E. SHELPS, *BORN TO DIE? DECIDING THE FATE OF CRITICALLY ILL NEWBORNS* 80 (The Free Press 1986).

utilized in newborn medical practice.³⁶ Historically, premature infants who struggled to survive or even breathe were provided with stabilization care so that the newborn “could declare itself a survivor or nonsurvivor.”³⁷ However, physicians capitalizing on the very latest in technology and treatment procedures have moved beyond the historic objective of simply providing better care to a modern “pushing the envelope” in extending the survivability of barely viable neonates.³⁸ Such actions have led some to label neonatologists as self-appointed guardians for the rights of the borderline infant—resulting in the diminution of compassion in favor of opportunism in hospital NICUs.³⁹ Even though medical progress has been made in the last thirty years to decrease morbidity rates of these infants, knowledge and experience of neonatologists in determining the neonates’ survival prognosis or likelihood of having severe handicaps remains problematic.⁴⁰

This Part of the Article examines the practical medical picture of an extremely premature infant who is presented to a neonatologist or other physician for medical treatment. These often-labeled “miracle workers” are looked to by hopeful parents desiring a healthy child. Physicians must not only assess the often hard medical facts of the infant when making a determination of what care (if any) to provide, but also juggle the emotional and psychological presence of less-medically-informed parents.

A. Evolution of the Neonatology Subspecialty

Medical and technological developments in the pediatric subspecialty of neonatology blossomed in the last century. Concentration on the newborn and attention paid to reducing the rate

36. *Id.*

37. *Id.* at 82.

38. See MacDonald et al., *supra* note 14, at 1024.

39. See Kaempf et al., *supra* note 14, at 23 (referring to physician William Silverman who believes some neonatologists’ decisions are trumping those of the infant’s parents).

40. See MacDonald et al., *supra* note 14, at 1024.

of infant mortality yielded a wealth of medical understanding ultimately used in clinical practice.⁴¹

Modern interest in the specialty care of newborns is traceable to Pierre Budin, a French obstetrician who, in 1892, established what today would be considered a well-baby clinic at Charite Hospital in Paris.⁴² Budin's focus was on the basic problems associated with premature birth including the infant's temperature, proper feeding, and preventing and treating diseases.⁴³ He used a warm-air incubator to keep premature infants warm, advocated breastfeeding in an amount more than twenty percent of the infant's body weight each day, and separated healthy and sick infants to guard against infection.⁴⁴

In the first half of the twentieth century, research on the pathology, physiology, clinical observations, growth, and outcomes of premature infants set the stage for technologically advanced NICU centers in major hospitals nationwide.⁴⁵ Pediatricians rather than obstetricians began providing more care for newborns.⁴⁶

The beginning of modern neonatology started approximately fifty years ago.⁴⁷ A booklet entitled *Standards and Recommendations for Hospital Care of Newborn Infants* was first published by the Committee on Fetus and Newborn (COFN) of the American Academy of Pediatrics (AAP) in 1948.⁴⁸ Four years later, Virginia Apgar presented a paper to multiple research societies about neonatal assessment in the delivery room and helped to focus attention on the newborn infant.⁴⁹ Then, in 1960, Alexander Schaffer, M.D., wrote a book on modern-day neonatology and is credited with coining the

41. SHELP, *supra* note 35, at 80.

42. *Id.*

43. *Id.*

44. *Id.*

45. *Id.* at 82.

46. *Id.*

47. Alistair G.S. Philip, *The Evolution of Neonatology*, 58 PEDIATRIC RES. 799 (2005).

48. *Id.*

49. *Id.*

term.⁵⁰ “Also in the early 1960s, an important distinction was made between small infants who were born ‘preterm,’ ([under] 38 [weeks of] gestation) and term infants who were small because of [other] growth restriction[s].”⁵¹

During the 1970s, newborn and maternal care improved. Mortality rates declined, in large part, due to the availability of intensive care for infants—including continuous monitoring of blood pressure, heart rate, and breathing rate.⁵² “Social workers were brought onto the neonatal team in an effort to ‘humanize’ care.”⁵³ And tougher questions were asked by ethicists about whether treatment should be initiated or withheld from severely disabled newborns.⁵⁴ In 1983, Nicholas Nelson, M.D., commented that advances in the practice of neonatology “brought the sick premature newborn infant to his present state of respectability as a patient to be cared for, rather than an object to be pitied.”⁵⁵

Historically, parents have had little choice of medical treatment for marginally-viable newborns due to the lack of effective medical knowledge.⁵⁶ Medicine, for all practical purposes, was unable to effectively intervene to rescue most of these patients.⁵⁷ Today, however, medical advances in treatments can now be used to transform many sick babies into healthy ones—from an infant at the edge of viability into a child with an uncertain quality of life. And it often starts with physicians assessing the single most important factors in extremely premature infants at the time of delivery—birth weight and gestational age.⁵⁸

50. *Id.* at 800; see also ALEXANDER J. SCHAFER, *DISEASES OF THE NEWBORN* (Mary E. Avery & H. William Taeusch, Jr. eds., W.B. Saunders Company 1960).

51. Philip, *supra* note 47, at 800.

52. Jeannine Wyszowski, *The Legal Rights of Disabled Infants to Receive Life-Sustaining Medical Treatment*, 4 CONN. PUB. INT. L.J. 181, 181–82 (2004).

53. SHEL, *supra* note 35, at 83.

54. *Id.*

55. See Philip, *supra* note 47, at 800 (citing N.M. Nelson, *Perinatal Medicine*, 1 HIST. R. & RECENT ADVANCES IN NEONATAL & PERINATAL MED., 3–8 (1983)).

56. SHEL, *supra* note 35, at 77.

57. *Id.*

58. *Id.* at 86; see also Jon E. Tyson et al., *Intensive Care for Extreme Prematurity—Moving Beyond Gestational Age*, 358 NEW ENG. J. MED. 1672, 1672 (2008); Nicholas S. Wood et al., *Neurologic and*

B. Categories of Extremely Premature Infants and Their Likelihood of Survival and Disability

Generally, premature infants are born at or before thirty-seven weeks of gestation—three weeks earlier than the forty weeks required of a full-term pregnancy.⁵⁹ Infants weighing under 2,500 grams, or nearly six pounds, at delivery are termed Low Birth Weight (LBW) infants.⁶⁰ Smaller newborns weighing under 1,500 grams, or nearly three and one-half pounds, at the time of delivery are termed Very Low Birth Weight (VLBW) infants.⁶¹ Finally, the most fragile infants, Extremely Low Birth Weight (ELBW), are those weighing less than 1,000 grams, or slightly over two pounds and are typically the youngest—born at twenty-seven weeks of gestation or less.⁶²

1. Infants Born Between Twenty-Two and Twenty-Seven Weeks of Gestation

“The application of neonatal intensive care to extremely premature infants, ([under] 27 weeks of gestation) is a fundamental controversy in neonatology.”⁶³ In most NICU centers nationwide, decisions on whether to provide intensive care are often made on the basis of the specific gestational age or weight of the infant.⁶⁴ In one study, male infants born at twenty-two weeks’ gestational age and weighing 600 grams had survival rates of approximately fifteen percent.⁶⁵ Often, the difficulty is medically seeing the marginally-viable newborn through his or her first thirty days of life that ultimately determines

Developmental Disability After Extremely Preterm Birth, 343 NEW ENG. J. MED. 378 (2000); MacDonald et al., *supra* note 14; William Oh et al., *supra* note 14; Timothy R. Cooper et al., *Actuarial Survival in the Premature Infant Less Than 30 Weeks’ Gestation*, 101 PEDIATRICS 975, 975 (1998).

59. George T. Mandy, *Incidence and Mortality of the Premature Infant*, UpToDate.com, http://www.uptodate.com/patients/content/topic.do?topicKey=c_PwZVBWkjEWHew (last visited Sept. 4, 2009).

60. *Id.*

61. *Id.*

62. *Id.*

63. Kaempf et al., *supra* note 14, at 23.

64. See Tyson et al., *supra* note 58, at 1672.

65. See MacDonald et al., *supra* note 14, at 1025.

survival.⁶⁶ Even those that initially survive often die shortly thereafter as a result of medical complications such as chronic lung disease, intracranial hemorrhage, and respiratory distress syndrome (RDS).⁶⁷ Thus, “the great majority of providers [do] not recommend resuscitation of premature infants born [before twenty-four weeks] of gestation.”⁶⁸

A recent medical study concluded that the likelihood of a favorable outcome for extremely premature infants provided with intensive care can better be estimated by consideration of four factors in concert with gestational age: sex of the infant, exposure or non-exposure to antenatal corticosteroids, whether born as part of a single or multiple birth, and birth weight.⁶⁹ If the infant was a single birth female with a slightly higher birth weight, the risk of death or impairment dramatically decreased.⁷⁰ Also, each one-week increase in gestational age significantly increased the infant’s chance of survival regardless of the sex of the child.⁷¹ The study, conducted on infants weighing less than 1000 grams at birth, reiterated physicians’ practice of providing “comfort care” to infants born at twenty-two weeks of gestation or less and only providing more aggressive care to infants born twenty-three to twenty-four weeks of gestation with parental agreement.⁷²

2. *Likelihood of Long-Term Disability*

The high adverse outcome rates for infants born at less than twenty-five weeks of gestation leads many physicians to question whether aggressive medical treatment, including resuscitation, should

66. See Cooper et al., *supra* note 58, at 976 (noting that in an actuarial study conducted on extremely premature infants, survival improved from 31% at birth to 58% on day 7 of life, and then to 75% on day of life 28).

67. See Kaempf et al., *supra* note 14, at 23.

68. *Id.* at 25.

69. See Tyson et al., *supra* note 58, at 1672.

70. *Id.*

71. *Id.*

72. *Id.* at 1673.

be provided to any of these extremely premature infants.⁷³ Even if the newborn survives, long-term neurodevelopmental outcomes are poor.⁷⁴ Often, the incidence of increased severe impairment including mental retardation, cerebral palsy, blindness and deafness accompanies survival.⁷⁵ According to one medical study conducted in 2003, ninety-two percent of infants born at twenty-three to twenty-four weeks of gestation had some moderate to severe abnormal neurologic, psychomotor, or mental development problems.⁷⁶ Rates of disability decreased with each additional gestational week of the newborn.⁷⁷

Birth weight also dramatically affects an infant's handicap prognosis. Infants with birth weights of less than 750 grams have a significant chance of experiencing long-term disabilities.⁷⁸ Almost eighty percent will experience some type of respiratory distress syndrome (RDS) and will need oxygen as long as twenty-eight days after birth.⁷⁹ Additionally, nearly one-half of all ELBW infants have some type of major neurosensory or neurodevelopmental impairment.⁸⁰

Doctors and hospital staff "must be willing to discuss the inability of current NICU care to prevent poor outcomes."⁸¹ Hospital and NICU medical guidelines and policies should reflect the need for physicians and other staff to have clear, consistent, and medically accurate discussions with parents regarding possible quality of life issues facing a newborn and to offer supportive treatment options

73. Monique Rijken et al., *Mortality and Neurologic, Mental and Psychomotor Development at Two Years in Infants Born Less Than 27 Weeks' Gestation: The Leiden Follow-Up Project on Prematurity*, 112 PEDIATRICS 351, 351 (2003).

74. See Kaempf et al., *supra* note 14, at 23.

75. *Id.* at 24.

76. See Rijken et al., *supra* note 73, at 351.

77. *Id.* Infants born at twenty-five weeks of gestation had a 64% chance of impairment; those born at twenty-six weeks had a 35% chance and those born between twenty-seven and thirty-two weeks had an 18% chance of some disability. *Id.*

78. Michael Battin et al., *Has the Outcome for Extremely Low Gestational Age Infants Improved Following Recent Advances in Neonatal Intensive Care?*, 15 AM. J. PERINATOLOGY 469, 476 (1998).

79. *Id.*

80. *Id.*

81. See Kaempf et al., *supra* note 14, at 28.

including comfort or palliative care alternatives.⁸² Further, physicians should consider how best to answer a parent's question about whether providing additional treatment would be futile.

C. The Difficulty in Defining Medical Futility

It is a very difficult to define medical futility, although there has been a good deal of medical and legal scholarship devoted to defining it in recent years.⁸³ The term has prompted many medical experts (and non-experts) to attempt to formulate a hard-and-fast definition to the term.⁸⁴ However, such attempts have only lead to increased confusion and to the conclusion that it is virtually impossible to identify a workable definition applicable to all cases.⁸⁵ Michael Ewer, M.D., offers the following definition of futility and notes its ineffectiveness:

Medical futility is the state that existed in a terminally ill patient for whom everything even remotely plausible, including heroic interventions, was subsequently tried, a patient for whom every proven and investigative therapeutic and supportive modality had been utilized, and who, despite all efforts (and not because of them) died. The fact that this definition is retrospective allows it to be ideally specific; no survivors can ever be treated in cases in which the criteria of medical futility will have been met. The

82. John M. Lorenz, *Compassion and Perplexity*, 113 PEDIATRICS 403, 404 (2004) (noting that parents are the rightful decision makers of medical treatment options for a child).

83. See generally Nora O'Callaghan, *Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act*, 60 BAYLOR L. REV. 527 (2008); Lisa L. Dahm, *Medical Futility and the Texas Medical Futility Statute: A Model to Follow or One to Avoid?*, HEALTH L. Aug. 2008, at 25; John M. Zerwas, Jr., *Medical Futility in Texas: Handling "Reverse Right-to-Die" Obstacles Without Constitutional Violation*, 43 TULSA L. REV. 169 (2007); Patrick Moore, *An End-of-Life Quandary in Need of a Statutory Response: When Patients Demand Life-Sustaining Treatment That Physicians Are Unwilling to Provide*, 48 B.C. L. REV. 433 (2007); Maureen Kwiecinski, *To Be or Not To Be, Should Doctors Decide? Ethical and Legal Aspects of Medical Futility Policies*, 7 MARQ. ELDER'S ADVISOR 313 (2006); Thomas William Mayo, *Living and Dying in a Post-Schiavo World*, 38 J. HEALTH L. 587 (2005).

84. See Mayo, *supra* note 83, at 600.

85. Michael S. Ewer, *The Definition of Medical Futility: Are We Trying to Define the Wrong Term?*, 30 HEART & LUNG 3 (2001).

definition is also totally useless in that it is clinically irrelevant; by the time we recognize futility to be present, the patient is already dead.⁸⁶

Ewer aptly reasons that in seeking a universal definition of medical futility, physicians are attempting to draw a hard line on a continuum.⁸⁷ Predicting whether a patient will defy statistical odds and improve when such improvement appears to be beyond the realm of possibility, is impossible.⁸⁸

Making medical futility determinations often includes analysis of statistical and physiologic variables affecting the patient. For example, does the infant have a twenty percent chance of survival if provided with a certain medical treatment? In the context of an extremely premature infant, if a physician concluding that a twenty-two week newborn has a ten percent chance of survival if provided with maximal medical intervention, the treatment cannot be said to be physiologically futile.⁸⁹ Thus, according to neonatologist Sadath Sayeed, such decisions at the time of birth are ethically problematic and speculative because they are made before any degree of certainty about the infant's diagnostic and prognostic outcomes can be properly ascertained through some medical treatment or intervention.⁹⁰

In the often ego-driven and emotional-charged specialty of neonatology, consensus regarding the probability of survival will always be in question regarding marginally-viable infants.⁹¹ Some physicians earnestly believe attempting to rescue an imperiled infant with only a ten percent chance of profoundly disabled survival to be

86. *Id.*

87. *Id.*

88. *Id.*

89. See Sadath A. Sayeed, *The Marginally-Viable Newborn: Legal Challenges, Conceptual Inadequacies, and Reasonableness*, 34 J.L. MED. & ETHICS 600, 604 (2006).

90. *Id.*

91. *Id.* at 605.

reasonable while others recommend against resuscitation of those infants with less than a fifty percent chance of intact survival.⁹²

Instead of a rigid term applicable to all cases, physicians should strive to define a meaningful cutoff point for when, in the course of treatment, continued therapeutic benefit is no longer reasonable.⁹³ In searching for such a cutoff point, neonatologists, using their education, background, and experience, must assess the infant's physical condition and balance a number of intersecting interests to make a medical determination of whether to provide a fragile newborn with aggressive, life-sustaining treatment or provide "comfort care," providing for the infant's basic needs but foregoing painful and therapeutically marginal medical procedures.

D. Physicians at the Crossroads of Intersecting Interests

When adversity afflicts a newborn, parents often turn to neonatologists whose powers are called upon to engender health for the infant. For suffering parents, the presence and reassurance of neonatologists can sometimes instill meaning to a situation that appears meaningless. Their task is to negotiate a medical reality for the infant that often includes pain, suffering, sickness, and perhaps death.⁹⁴ Sometimes, parents and physicians conflict in what each believes is the proper course of medical action or when a parent refuses to let go of a life. Thus, physicians are often placed at an intersection of competing interests. Not only must they do what is in the best medical interests of the newborn, but often they must act as counselors to parents—providing comfort, reassurance, and hope. They also are frequently looked upon by a third party or governmental agency that may not only seek to override their treatment decisions, but also bring civil or criminal charges against them if they act improperly.⁹⁵ The specific identification and rank-

92. *Id.*

93. See Ewer, *supra* note 85, at 3–4.

94. See SHELFP, *supra* note 35, at 88.

95. *Id.* at 91.

order of these often competing interests may never be identical from one physician to the next or from one case to the next.⁹⁶

A physician advising a parent that he or she has done everything medically possible and additional treatment provided to the newborn would likely have no beneficial effect is sometimes met with resistance and insistence by the parents that more is done to allow the baby to survive. Such beliefs from a parent may arise from an unwillingness to let a child go, from a sincere belief that some treatment must be beneficial, and often from a belief that the child's life is worth preserving at all costs—even if continued treatment may inflict pain and suffering.

III. THERAPEUTIC ILLUSIONS AND THE ROLE OF VITALISM: PRESERVING LIFE AT ANY COST

Most parents heed the medical advice provided by treating physicians who recommend that no treatment be provided because an infant's life (should it be saved) would be too compromised to be worth the effort.⁹⁷ In some cases, however, the collaborative decision-making approach between parent and physician is ineffective due to a core emotional belief of the parent that the infant's life should be preserved at all costs. A parent does not want to give up hope that a child may survive or that a cure can be found. It is difficult to argue with the notion that a parent would seek out every medical possibility to ensure the survival of his or her child. Some parents often endlessly pursue aggressive treatment for an infant that will provide no beneficial end. They do this because they refuse to acknowledge the grim reality of the infant's medical condition, they believe that the child will ultimately improve medically, or they seek to uphold the sanctity of the infant's life at any cost.

96. *Id.* at 92.

97. Sayeed, *supra* note 89, at 608.

This Part of the Article examines two parent-focused belief and value systems that can dramatically impact the future of an ailing extremely premature infant. The first, known as therapeutic illusion, is the psychological belief that continued medical treatment is (or will be) beneficial to the infant, even in light of medical evidence that suggests otherwise. The second, vitalism, is the value system that holds the sanctity of life should be upheld irrespective of the potential harm caused to the infant and despite the financial, emotional, or psychological costs incurred. It will further analyze two legal battles waged between a parent demanding medical treatment be provided to her child and health-care facilities refusing. Though they are not cases dealing with extremely premature infants, Sun Hudson and Emilio Gonzales reflect the conflict resulting from a parent who, as a result of a therapeutic illusion or vitalist beliefs, ignores the bleak medical reality facing her child in favor of the idea that the child's life, regardless of quality, must be preserved.

A. Therapeutic Illusions: Hope in the Face of Stark Medical Reality

Medical ethicist William Winslade artfully states that our culture's common belief, when faced with the prospect that a loved one's medical treatment may be futile, is to "never give up hope," despite current medical literature and standards.⁹⁸ Such a belief has been coined a "therapeutic illusion," a phenomenon first labeled by K.B. Thomas.⁹⁹ According to Thomas, a "doctor himself is a powerful therapeutic agent," who often equates slight improvement of a medical condition to the treatment being provided—even when it is not true.¹⁰⁰ Thus, parents often grasp onto the false notion that their child's health is improving as a result of the diagnosis made by a

98. See William J. Winslade, *What to Do With Our Real-Life Rip Van Winkles?*, HOUS. CHRON., Apr. 11, 1996, at 25A; see also Stacey A. Tovino & William J. Winslade, *A Primer on the Law and Ethics of Treatment, Research, and Public Policy in the Context of Severe Traumatic Brain Injury*, 14 ANNALS HEALTH L. 1, 27 (2004).

99. K.B. Thomas, *The Consultation and the Therapeutic Illusion*, 1 BRIT. MED. J. 1327, 1328 (1978).

100. *Id.*

physician and the treatment subsequently provided.¹⁰¹ Even in the face of clear and undeniable facts that further medical treatment would not be beneficial, family members often hold out hope that their child will “beat the odds.”¹⁰²

Health-care providers “not infrequently find themselves in the conundrum of providing futile care to a hopelessly ill patient.”¹⁰³ It is a frustrating endeavor made worse by the possibility that family members may seek continued medical treatment indefinitely.¹⁰⁴ There is often very little a physician can say or do to alter the therapeutic illusion of a parent who adamantly believes in the power of hope against all odds.

B. Vitalism: Life As an Intrinsic Good To Be Preserved

Similar to the concept of therapeutic illusion, a parent may believe that his or her infant’s life, regardless of the pain endured, is a good worth preserving in and of itself.¹⁰⁵ Instead of relying on a false notion that a course of medical treatment is beneficial to the patient, a vitalist holds the deeply personal belief any human life is precious and should be prolonged as long as possible at any cost despite the grim medical reality facing the infant.¹⁰⁶

101. *Id.*

102. See Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 11 (2007); see also Clare Dyer, *Doctors Need Not Ventilate Baby to Prolong His Life*, 329 BRIT. MED. J. 995, 995 (2004) (reporting that two mothers of terminally ill infants rejected medical advice because their babies were “‘fighters’ . . . [and] had lived longer than doctors had predicted”); Todd Ackerman, *Hospital Rules to Unplug Baby Girl: Leukemia Patient’s Parents Scramble to Find New Care Facility*, HOUS. CHRON., Apr. 30, 2005, at B1 (reporting that the mother of Knya Dismuke-Howard, a six-month old girl with leukemia in her brain, multiple organ failure, and a life-threatening antibiotic-resistant infection stated, “I think she can beat the odds . . . She’s a fighter . . .”).

103. Stanley A. Nasraway, *Unilateral Withdrawal of Life-Sustaining Treatment: Is It Time? Are We Ready?*, 29 CRITICAL CARE MED. 215, 215 (2001).

104. *Id.*

105. See Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 442–43 (1988) (“A vitalist believes that life, in and of itself, is a good worth preserving.”).

106. Tovino & Winslade, *supra* note 98, at 26–27; see also WILLIAM J. WINSLADE, CONFRONTING TRAUMATIC BRAIN INJURY: DEVASTATION, HOPE, AND HEALING 25, 117 (1999); see generally Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1 (2004) (arguing against a vitalist approach).

As evidenced by the passage of the Baby Doe regulations in the early 1980s, vitalism is deeply entrenched in our culture.¹⁰⁷ A strict vitalist asserts that life itself is paramount to any quality-of-life considerations and would dictate the continuation of medical treatment even if to do so would be extraordinarily painful or intrusive.¹⁰⁸ “The vitalist aggressively defends human biological existence.”¹⁰⁹

Individuals holding a vitalist view often do so as the result of religious or moral instruction. Historically, the Judeo-Christian tradition has attempted to place medical vitalism on a continuum—a “middle path” between preserving life at all costs and ending life when it seemed futile.¹¹⁰ Roman Catholic theologian Richard McCormick notes that life is indeed a precious good, but a relative one, and the duty to preserve it, a limited one.¹¹¹ “These limits have always been stated in terms of the *means* required to sustain life.”¹¹² Pope Pius XII recognized the limits of providing medical treatment in futile cases.¹¹³ However, in recent years, the Catholic Church has promoted a more rigid approach to the sanctity of life issue. In the context of the abortion discussion, Pope John Paul II approved an instruction on respect for human life which read in part:

107. See generally Ouellette, *supra* note 106.

108. Leslie Pickering Francis & Anita Silvers, *(Mis)Framing Schiavo As Discrimination Against Persons with Disabilities*, 61 U. MIAMI L. REV. 789, 817 (2007); see also Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549, 568 (1997).

109. Ouellette, *supra* note 106, at 21 (quoting Larry Gostin, *A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates*, 11 AM. J.L. & MED. 31, 37 (1985)).

110. RICHARD A. MCCORMICK, *To Save or Let Die: The Dilemma of Modern Medicine*, in BIOETHICS: AN INTRODUCTION TO HISTORY, METHODS, AND PRACTICE 70, 72 (Nancy S. Jecker, Albert R. Johnson, & Robert A. Pearlman eds. 1997); see also Gostin, *supra* note 109, at 37 (Gostin defines a continuum of vitalist thought from the most robust or pure, requiring all heroic or extraordinary measures, to the more moderate which “recognizes that decisions affecting individual human life are already made as a consequence of allocating scarce health care resources”).

111. MCCORMICK, *supra* note 110, at 72.

112. *Id.*

113. *Id.* In an allocution to physicians in 1957, the Pontiff noted that only ordinary means are required to preserve life: “A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult.” *Id.*

The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his rights as a person must be recognized, among which in the first place is the inviolable right of every innocent human being to life.¹¹⁴

Thus, it can be argued that Pope John Paul II was a strict vitalist—holding “non-treatment as intentional termination of life, which is prohibited. Consequently, [he] would mandate continued medical treatment in every instance, irrespective of the patient’s condition.”¹¹⁵ Conversely, Pope Pius XII could be said to have been a moderate vitalist—recognizing a justifiable decision to let an infant die when the costs of preserving life were overly burdensome and deemed extraordinary and nonobligatory.¹¹⁶

Those holding more moderate vitalist views when faced with making medical decisions on behalf of a marginally-viable infant allow for discussion regarding the future quality of life of the child. Entering into the equation is the extent to which the child will have meaningful human relationships. McCormick advocates that a life is possibly not worth living if such “human relationships . . . would be so threatened, strained, or submerged that they would no longer function as the heart and meaning of an individual’s life”¹¹⁷ He adds that it is neither inhuman nor unchristian to say that there comes a point where an individual’s medical condition renders the person unable to have any human relationship potential:

When that point is reached, is not the best treatment, no treatment? In this tradition, life is not a value to be preserved in and for itself. To maintain that would commit us to form of

114. Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation Replies to Certain Questions of the Day* (Feb. 22, 1987), http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html.

115. See Boozang, *supra* note 108, at 568.

116. See MCCORMICK, *supra* note 110, at 72–73.

117. *Id.* at 73.

medical vitalism that makes no human or Judeo-Christian sense. It is a value to be preserved precisely as a condition for other values, and therefore insofar as these other values remain attainable. Since these other values cluster around and are rooted in human relationships, it seems to follow that life is a value to be preserved only insofar as it contains some potentiality for human relationships.¹¹⁸

However, a parent making such a decision on behalf of a child is asked to give up, give in, and let go of hope; it is a decision parents are often not willing to make. Wanda Hudson, the mother of Sun Hudson, refused to consent to the withdrawal of life-sustaining medical treatment being provided to her ailing son.

C. The Case of Sun Hudson

In 2004, a severely disabled and dying infant born in Houston, Texas, became the focus of widespread media attention when a mother demanding treatment be provided to her son was pitted against physicians and a health-care facility that believed life-sustaining care was adding to the child's suffering.¹¹⁹ Wanda Hudson believed that her son's condition would improve, despite medical evidence that undoubtedly indicated otherwise.

Sun Hudson was born at St. Luke's Episcopal Hospital with short appendages, an enlarged head, and significant respiratory distress.¹²⁰ Sun's mother, Wanda, had received no prenatal care prior to giving birth and was unaware that her son would be born with significant physical and mental disabilities.¹²¹ Sun was immediately transferred to Texas Children's Hospital where he was placed on a respirator and a feeding tube was inserted.¹²² Genetic testing revealed that Sun was

118. *Id.* at 131.

119. See Zerwas, *supra* note 83, at 179–80.

120. Lance Lightfoot, *Incompetent Decisionmakers and Withdrawal of Life-Sustaining Treatment: A Case Study*, 33 J.L. MED. & ETHICS 851, 852 (2005).

121. *Id.*

122. *Id.*

born with thanatophoric dysplasia, a rare and fatal condition affecting some 60,000 births.¹²³ Most infants affected by the condition die shortly after birth because the baby's narrow chest cavity restricts its ability to breathe—slowly worsening until the infant suffocates to death.¹²⁴ Additionally, most infants with the condition have severe mental and physical disabilities.¹²⁵

Complicating matters was Wanda's insistence that her son was a "special" child and conceived by the sun in the sky, not by another human.¹²⁶ Shortly after giving birth, Wanda was involuntarily committed to a psychiatric hospital for evaluation; however, not finding her to be a threat to herself or others, she was released and resumed visiting her son at Texas Children's Hospital.¹²⁷ Upon her return, Sun's physicians informed Wanda of his condition, his negative prognosis, and recommended the withdrawal of life-sustaining care.¹²⁸ Wanda refused and accused physicians and nursing staff of wanting to murder him.¹²⁹ Additionally, members of the hospital's social work department and clergy spoke with Wanda in an effort to assist her in coping with her son's likely death.¹³⁰ Wanda steadfastly refused to acknowledge the medical facts affecting her son, advice given by the treating physicians, and simply prayed for a change.¹³¹

Fewer than two months later, the Texas Children's Hospital Bioethics Committee convened to discuss Sun's case as an example of medically inappropriate treatment being provided and causing the

123. *Id.*; see also Dahm, *supra* note 83, at 28.

124. Lightfoot, *supra* note 119, at 852.

125. *Id.*

126. *Id.*

127. *Id.*

128. *Id.*

129. See Dahm, *supra* note 82, at 28.

130. Lightfoot, *supra* note 120, at 852.

131. *Id.*; see also Leigh Hopper, *No Easy Calls When Baby Is Terminally Ill: Local Case Casts Light on Dilemma of Hospitals, Parents in Disputes Over Ending Treatment*, HOUS. CHRON., Feb. 9, 2005, at A1.

child excessive pain.¹³² The committee, following Texas law,¹³³ notified Wanda that it would discontinue medical care of Sun within ten days, unless another health-care facility could be located to accept transfer of the infant.¹³⁴ After being granted several extensions by the hospital to locate a facility willing to accept Sun, Wanda was finally denied a final extension and thereafter sought legal counsel.¹³⁵ Concerned that Wanda did not fully understand the gravity of the situation, the hospital assisted her in obtaining (and paying the legal fees of) an attorney.¹³⁶

Wanda Hudson sued Texas Children's Hospital seeking injunctive relief and monetary damages.¹³⁷ Specifically, Wanda sought an order requiring the hospital to provide continued life-sustaining treatment to her son.¹³⁸ A temporary injunction requiring the hospital to provide continued care for five months was granted.¹³⁹ However, on March 14, 2005, the probate judge hearing the case held there was no reasonable expectation that another health care provider would agree to continue treatment if time were extended.¹⁴⁰ The ruling essentially allowed the hospital to withdraw the life-sustaining treatment keeping Sun alive. On March 15, 2005, Texas Children's Hospital removed Sun's life support and he died moments later in his mother's arms.¹⁴¹

Neonatologist Sadath Sayeed recognizes the inherent difficulty parents like Wanda Hudson face when attempting to decide the fate of their child's life:

. . . [T]his 'intractable' bioethical dilemma does start with the recognition that *parents*, not physicians, bioethicists, or judges,

132. See Amir Halevy & Amy L. McGuire, *The History, Successes and Controversies of the Texas "Futility" Policy*, 43 HOUS. LAW. 38, 40 (2006); see also *Hudson v. Tex. Children's Hosp.*, 177 S.W.3d. 232, 233 (Tex. App. 2005).

133. See TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Texas Advance Directives Act).

134. See Halevy & McGuire, *supra* note 132, at 40.

135. See Moore, *supra* note 83, at 461.

136. *Id.*

137. See *Hudson*, 177 S.W.3d. at 234.

138. *Id.*

139. See Halevy & McGuire, *supra* note 132, at 40.

140. *Id.*

141. See Moore, *supra* note 83, at 461.

are forced to gamble (with rather poor odds) sacrificing their own child's life as well as their own life projects because of the ready availability of sophisticated medical technology and skill

¹⁴²

....

Even a parent who is not under a therapeutic illusion will have an agonizing choice to let his or her child die without ensuring that all medical options to cure or save have been exhausted.¹⁴³ The inherent slippery-slope, however, is that physicians, upon the demands of a parent, may initiate a therapeutic course of action even though saving a marginally-viable infant is statistically improbable.¹⁴⁴ Another Texas case highlights the inherent conflict between parent and health-care provider.

D. The Case of Emilio Gonzales

Approximately eight months after the death of Sun Hudson, Emilio Gonzales was born blind, deaf, and developmentally delayed in Austin, Texas.¹⁴⁵ Emilio suffered from Leigh's Disease, a rare, inherited, and fatal neurometabolic disorder that collapses the individual's central nervous system.¹⁴⁶ The progressive disorder begins in infants between the ages of three months and two years.¹⁴⁷ Early signs of the disease include loss of head control and motor skills, seizures, and poor sucking ability.¹⁴⁸ As the disorder progresses, the individual loses muscle tone and incurs episodes of lactic acidosis—leading to respiratory and kidney function impairment.¹⁴⁹ Although there is limited treatment consisting of the

142. See Sayeed, *supra* note 89, at 607.

143. *Id.* at 608.

144. *Id.*

145. Mary Ann Roser, *Boy's Short Life to Have Lasting Impact*, AUSTIN AM.-STATESMAN, May 21, 2007, at B1.

146. Nat'l Inst. of Neurological Disorders & Stroke, NINDS Leigh's Disease Information Page, <http://www.ninds.nih.gov/disorders/leighsdisease/leighsdisease.htm> (last visited Nov. 15, 2008).

147. *Id.*

148. *Id.*

149. *Id.*

administration of thiamine or Vitamin B1, the prognosis for infants with Leigh's Disease is poor.¹⁵⁰ Some individuals with a less severe case have lived to six or seven years of age.¹⁵¹ Unfortunately, Emilio's case was more advanced.

On December 27, 2006, at approximately twelve months of age, Emilio was admitted to the Pediatric Intensive Care Unit (PICU) of Children's Hospital of Austin, Texas, suffering from a collapsed lung; he was placed on a ventilator and a nasogastric tube was inserted.¹⁵² Without assistance from the ventilator, Emilio would die within minutes or hours.¹⁵³ For the next several months, heavy doses of medication were administered to the fragile infant.¹⁵⁴ While Emilio's mother, Catarina, was sure that her infant son would often smile, a hospital nurse believed that he was grimacing in pain.¹⁵⁵

Attending physicians and hospital staff attempted to discuss Emilio's certain fate with his mother, but Catarina was resistant to the recommendation that her son's life support be discontinued.¹⁵⁶ Often combative with hospital staff, she called them "murderers."¹⁵⁷ However, after several months of treatment physicians believed to be futile and painful,¹⁵⁸ the hospital's Ethics Committee concluded that continued aggressive treatment was unwarranted and sought to invoke the Texas Advance Directives Act—allowing the hospital to discontinue Emilio's life support.¹⁵⁹ Hospital officials attempted to find a facility willing to accept Emilio "without any single indication

150. *Id.*

151. *Id.*

152. Eileen E. Flynn, *Dying Boy's Case Likely to Reverberate in Law, Religion*, AUSTIN AM.-STATESMAN, Apr. 15, 2007, at A1.

153. Sylvia Moreno, *Case Puts Texas Futile-Treatment Law Under a Microscope*, WASH. POST, Apr. 11, 2007, at A3.

154. *Id.*

155. Elizabeth Cohen, *Fight Over Baby's Life Support Divides Ethicists*, CNN.com, Apr. 25, 2007, <http://www.cnn.com/2007/HEALTH/04/25/baby.emilio/index.html> (last visited Nov. 15, 2008).

156. Mary Ann Roser, *A Young Life, Already Shortened, in Dispute at Hospital*, AUSTIN AM.-STATESMAN, Mar. 7, 2007, at A1.

157. *Id.*

158. See Mary Ann Roser, *Child's Guardian Supports Doctors, Hospital*, AUSTIN AM.-STATESMAN, May 9, 2007, at B1.

159. See Dahm, *supra* note 83, at 29; see also Robert D. Truog, *Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1 (2007).

of interest in taking the transfer.”¹⁶⁰ Catarina Gonzales countered by filing a lawsuit against the hospital asking that the court find the Texas law unconstitutional and requesting that the hospital continue to provide life-sustaining treatment.¹⁶¹ During the pendency of the lawsuit, Emilio died in his mother’s arms on May 19, 2007, before the judge could make a final ruling.¹⁶²

E. Who Should Decide? Conflicting Views

Although the Texas Advance Directives Act was the legal means utilized in the Sun Hudson and Emilio Gonzales lawsuits to challenge the withdraw of life support, the crux of the debate centered on who had the right to determine whether futile care should continue. In Emilio’s case, Michael Regier, Senior Vice President for Legal Affairs and general counsel for the Seton Family of Hospitals, of which Austin Children’s Hospital is a member, said that the treatment provided was inflicting suffering upon the infant.¹⁶³ “We are inflicting harm on this child. And it is harm that is without a corresponding medical benefit.”¹⁶⁴ But Emilio’s mother disagreed saying that her son was on heavy doses of morphine and was not in any pain.¹⁶⁵

Emilio’s case generated heated discussions among medical experts, ethicists, and others with experiences similar to that of Catarina Gonzales. Even the siblings of Terri Schiavo, the Florida woman in a persistent vegetative state who generated national debate when family members disagreed over the continuation of futile medical treatment, weighed in and supported Ms. Gonzales.¹⁶⁶ Art Caplan, an ethicist at the University of Pennsylvania who supported the hospital, stated that

160. Moreno, *supra* note 153, at A3.

161. Dahm, *supra*, note 83, at 29.

162. *Id.*; see also Mary Ann Roser, *Emilio’s Life Raises Issues of Care’s Cost*, AUSTIN AM.-STATESMAN, May 28, 2007, at B1.

163. Cohen, *supra* note 155.

164. *Id.*

165. *Id.*

166. Moreno, *supra* note 153.

sometimes “family members just don’t get it right.”¹⁶⁷ “No parent should have the right to cause suffering to a kid in a futile situation,” said Caplan.¹⁶⁸ But Lainie Ross, a pediatrician and medical ethicist at the University of Chicago, stated that Emilio’s mother, not the treating physicians or health-care facility, ought to decide the medical treatment path for her son.¹⁶⁹ “Who am I to judge what’s a good quality of life?” said Ross.¹⁷⁰ “If this were my kid, I’d have pulled the ventilator months ago, but this isn’t my kid.”¹⁷¹

Even religious figures failed to reach a consensus regarding whether Emilio’s life support should be discontinued. Bishop Gregory Aymond, of the Austin Catholic diocese, stated that “[t]he Catholic Church would teach if there is no possibility of recovery, that extraordinary means can be withdrawn, and it’s not taking the life of a person, but simply allowing them to die naturally and with dignity.”¹⁷² However, orthodox Father John Trigilio disagreed slightly, writing:

This is a difficult case The moral obligation is always to give normal care and use ordinary means to treat the sick and the dying Extraordinary means, like the ventilator, may be refused while ordinary means cannot be refused. Once in place, however, if the extraordinary means are sustaining life, I do not think it is morally permissible to remove already operational extraordinary means Once the respirator (or ventilator) is turned on . . . I do not think it can be turned off if it will directly cause death Preventing death is not always obligatory when

167. Cohen, *supra* note 155.

168. *Id.*

169. *Id.*

170. *Id.*

171. *Id.*

172. Jim Bergamo, *Ethical, Moral Questions Over Life Support Fight*, KVUE.com, Apr. 19, 2007, <http://www.kvue.com/news/local/stories/041907kvueemilio-bkm.26766bcb.html>.

there is no reasonable hope of recovery, but directly causing death is always considered killing and is therefore immoral.¹⁷³

In Emilio's case, such discussion was not welcomed by the infant's mother, Catarina, who refused to heed *any* advice provided by clergy, physicians, or others recommending withdrawal of life-sustaining treatment. Catarina stated, "every moment of life he [had] to spend with *her* [was] of inestimable value."¹⁷⁴ Catarina's belief that Emilio's life was worth preserving was actually, in part, a self-centered notion while ignoring the bleak medical reality facing her child.¹⁷⁵ To Catarina, her son's life (whether he was in pain or not) had immense value.

There is little doubt that, aside from the opinions of pro-death penalty advocates, life should be preserved when possible. It is an entity to be cherished. After all, religious, moral, and ethical teachings instruct us not to commit murder and to otherwise do no harm. Often, however, some lives of extremely premature and marginally-viable infants are fraught with pain, suffering, and struggling to survive at the edge of life. If providing medical treatment would be beneficial in assisting the infant on his or her meaningful life path, based upon prevailing medical standards and the facts presented, then it should be provided. However, there often comes a point when a newborn's medical condition renders the child unable to have any human relationship potential. In those gray areas surrounding the unknown future of a marginally-viable infant, physicians and parents often turn to the ethical norm: the 'best interests' of the child, to guide medical decision-making.

173. Matt C. Abbott, *Priest-author Comments on Emilio Gonzales Case*, RENEW AM., Apr. 23, 2007 (on file with author).

174. Verified Complaint, *Gonzales v. Seton Family of Hosp.*, No. A07CA267, 2007 WL 1622769 at *3 (W.D. Tex. Apr. 4, 2007) (emphasis added).

175. See Francis & Silvers, *supra* note 108.

IV. MAKING DECISIONS IN THE BEST INTERESTS OF THE INFANT

The inherent difficulty in fashioning a workable definition of medical futility, in part, can similarly be found in a lack of consensus surrounding the Best Interests Standard used when making medical treatment determinations on behalf of a marginally-viable newborn.¹⁷⁶ Although the concept of best interests is well-accepted in pediatric ethics, debate and controversy often arises in practice regarding *how* one may determine an infant's best interests.¹⁷⁷ Should it be the physician deciding what is in the best interests of an imperiled newborn, or the child's parents? The standard seemingly invokes a combination of practical, medical facts from the physician and philosophical, moral, and quality-of-life factors from the parents. This Part of the Article examines the Best Interest Standard from both the physician's and parents' perspective when faced with making medical decisions on behalf of an extremely premature infant and how to best reach a consensus.

A. *The Controversy Surrounding the Standard*

Medical experts agree the goal of neonatal medicine is to minimize both over-treatment and under-treatment of the extremely premature infant and to approach a medical decision-making process in the best interests of the infant.¹⁷⁸ However, as is the case with defining medical futility, there is no widespread agreement on how best to employ the term.¹⁷⁹ Professor Loretta Kopelman notes that some commentators believe the standard requires ideal treatment be provided and nothing less.¹⁸⁰ Others, including Kopelman, argue such

176. See Sayeed, *supra* note 89, at 605; Ferdinand D. Yates, Jr., *Medical Decision Making for the Marginally Viable Infant*, 10 VIRTUAL MENTOR 673, 674 (2008), available at <http://virtualmentor.ama-assn.org/2008/10/oped1-0810.html> (last visited Nov. 13, 2008).

177. Steven R. Leuthner, *Decisions Regarding Resuscitation of the Extremely Premature Infant and Models of Best Interest*, 21 J. PERINATOLOGY 193, 197 (2001).

178. *Id.* at 193.

179. See Kopelman, *supra* note 23, at 187.

180. *Id.* (citing R.M. Veatch, *Abandoning Informed Consent*, HASTINGS CENTER REP., Mar. 2005, at 32).

a rigid explanation is impractical; instead, she argues, the standard requires a decision maker to do what is reasonable given the circumstances.¹⁸¹ Kopelman states:

The Best Interests Standard should be understood as an umbrella principle covering different kinds of usage It can be employed to express moral, legal, medical, or other social goals or ideals that should guide choices Second, it can be used in making practical and reasonable decisions about what should be done in a particular situation, given the available (and usually less than ideal) options.¹⁸²

However, one vague term apparently leads to another; what may be reasonable to a physician may not be equally reasonable to a parent. The seemingly endless number of questions generated from determining the best interests of a borderline neonate has led some physicians to dismiss the standard altogether. The former chairperson of the AAP Committee on Bioethics, Joel Frader, has stated:

I doubt that insisting on the reliance on the Best Interests Standard gets us very far. Best interests, similar to art or pornography, tends to mean whatever the beholder believes it to mean. The term has no independent substance, and we should not fool ourselves into thinking that it alone improves decision-making.¹⁸³

Indeed, the best interests of a newborn in the eye of a physician may be drastically different when viewed by a parent. There are thus two reasonable, yet competing interpretations of what is in the best interests of the infant.¹⁸⁴ The stalemate, however, does not resolve

181. *Id.*

182. *Id.*

183. See Sayeed, *supra* note 89, at 605; see also Joel E. Frader, *Baby Doe Rules: In Reply*, 116 PEDIATRICS 1601-02 (2005).

184. See Sayeed, *supra* note 89, at 606.

how best to approach a dire medical situation facing a marginally-viable newborn. Ethicist John Paris, a long-time advocate for retaining informed parental and physician choice in cases of extremely premature infants, has argued that each actor, physician and parent, must reach a consensus using their respective areas of expertise—medical facts and prognosis from the physician and moral, religious, and quality-of-life concerns from the parents—to determine what is in the best interests of the infant:

There is now a strong consensus in the medical, legal, and ethical literature that it is the best interests of the infant—not the desires of the parents or the determination of the physician—that must prevail in the care of newborns Translated into practice, this standard means that if the burden on the infant is overwhelming or the prospects are extremely bleak, as is true in the presence of a lethal abnormality, there is no obligation to subject the infant to further procedures.¹⁸⁵

Collaboration among physicians and parents best allows for a determination of what is overwhelmingly bleak in each circumstance. The probability that an infant will expect a lifetime of mental retardation or blindness does not necessarily translate into a life not worth living, let alone deemed overwhelmingly bleak, to some parents.¹⁸⁶ A best interests analysis may be easiest when death is inevitable for there is little uncertainty regarding the infant's future. Such is not the case when an imperiled newborn has a ten percent chance of surviving, if severely disabled, through rescue treatments.¹⁸⁷ The questions and decision-making only get more difficult in such situations.

185. John J. Paris, Michael D. Schreiber, & Frank E. Reardon, *Ethical and Legal Issues*, in ASSISTED VENTILATION OF THE NEONATE 81 (Jay P. Goldsmith & Edward H. Karotkin, eds.) (4th ed. 2003).

186. See Sayeed, *supra* note 89, at 605.

187. *Id.*

B. The Appropriate Best Interests Approach

One of the most widely accepted methods of using the Best Interests Standard is a shared decision making process in which the physician, using his or her medical expertise, guides the family through the treatment process, adhering, as much as possible, to the parents' value system.¹⁸⁸ Steven Leuthner, M.D., argues:

We must allow parents to interpret the meaning of the prognosis given and decide for their children. We, as physicians, must recognize our moral agency. We may agree or disagree with parental values, but we must work with parents and within societal and professional rules in deciding what actions determine best interest.¹⁸⁹

When a borderline case is evident, the physician should collaborate with the parents and jointly explore the infant's medical diagnosis and prognosis in the confines of parental values and morality. This "negotiated model" encourages "an enhanced autonomy that consists of listening to and sharing perspectives, accepting the physician's authority to offer recommendations, and obligating physicians to fully understand parental reasoning."¹⁹⁰ In doing so, writes Leuthner, the child as a whole is fully valued—not simply the life of the child.¹⁹¹

The negotiated model has its drawbacks, however. It may allow parental values to always prevail in conflicts over decision making. Parental love can have different motives and potential pathology, creating conflict between the medical team and the parent. Vitalist beliefs or therapeutic illusions expressed by a parent may demand aggressive medical treatment be provided to an ailing infant though an experienced neonatal team finds such treatment to be medically

188. See Leuthner, *supra* note 177, at 196.

189. *Id.*

190. *Id.* at 197.

191. *Id.*

inappropriate or even cause pain and suffering. Physicians and health-care facilities should be prepared for such scenarios through comprehensive hospital policies and guidelines.

Other factors, such as federal law, additionally affect treatment decisions of an extremely premature infant and are often dismissive of the Best Interests Standard. The Baby Doe rules enacted in the early 1980s are representative of such initiatives.

V. THE BABY DOE SAGA

The quandary of neonatal rescue medicine intensified in the early 1980s, when governmental intervention in treatment decisions involving critically ill newborns became a matter of widespread public concern. The most notorious of the cases involved a disabled infant born on April 9, 1982, in Bloomington, Indiana.¹⁹² Forever to be known as Baby Doe, the infant was diagnosed with Down syndrome and a tracheoesophageal fistula—a condition preventing oral feeding.¹⁹³ Without necessary surgery to repair the handicap, Baby Doe was certain to die. The newborn's parents were told by the obstetrician that "if the surgery were performed and if it were successful and the child survived, that this still would not be a normal child. That it would still be a mongoloid, a Down syndrome child with all the problems that even the best of them have."¹⁹⁴

The parents refused to consent to treatment, and hospital staff sought a court order to override the parents' decision.¹⁹⁵ The Indiana Supreme Court ruled that the parents had the right to make medical decisions on behalf of their child.¹⁹⁶ Baby Doe died on April 15,

192. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir., Ind. Apr. 12, 1982) (deferring to parental decision to withhold treatment for a disabled newborn), *cert. denied*, 464 U.S. 961 (1983); see also George J. Annas, *The Baby Doe Regulations: Governmental Intervention in Neonatal Rescue Medicine*, 74 AM. J. PUB. HEALTH 618, 618 (1984).

193. See Annas, *supra* note 192, at 618.

194. See Bagenstos, *supra* note 20, at 429 (citing U.S. COMM'N ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES 21–23 (1989)).

195. *Id.*

196. *Id.*

1983, when he was six days old.¹⁹⁷ The court's decision sparked outrage among right to life and disability groups.¹⁹⁸ Soon after, President Ronald Reagan weighed in on the issue and inserted his influence into medical decision-making by enacting regulations in an attempt to prevent future Baby Doe cases from occurring. Public discussion and debate ensued, bringing normative neonatal medical practice from the NICU into the public domain.

This Part of the Article chronologically examines how the Baby Doe regulations have evolved in the past twenty-five years and their resulting impact on modern treatment decisions involving marginally-viable newborns.

A. President Reagan's Public Response to the Baby Doe Decision

In the spring of 1983, President Ronald Reagan penned an article for *The Human Life Review*, in which he reflected on the tenth anniversary of the United States Supreme Court's decision in *Roe v. Wade*.¹⁹⁹ Arguing that "abortion-on-demand is not a right granted by the Constitution," President Reagan called for the American people to steadfastly express their opinions that *all* human life is sacred and, thus, worth preserving at all costs.²⁰⁰ "Once we as a nation . . . affirm the sanctity of life, we will see the importance of affirming this principle across the board," wrote Reagan.²⁰¹

President Reagan did not, however, limit his pro-life comments to the debate surrounding abortion. He proactively denounced any argument offered in favor of the "quality of life" ethic potentially affecting premature and disabled newborns at the edge of viability.²⁰² "It is not for us to decide who is worthy to live and who is not," wrote Reagan.²⁰³ Reagan argued:

197. *Id.*

198. See Annas, *supra* note 192, at 618.

199. Ronald Reagan, *Abortion and the Conscience of the Nation*, THE HUM. LIFE REV., <http://www.nationalreview.com/document/reagan200406101030.asp> (last visited Nov. 23, 2008).

200. *Id.*

201. *Id.*

202. *Id.*

203. *Id.*

Every legislator, every doctor, and every citizen needs to recognize that the real issue is whether to affirm and protect the sanctity of all human life, or to embrace a social ethic where some human lives are valued and others are not. As a nation, we must choose between the sanctity of life ethic and the 'quality of life' ethic.²⁰⁴

In advocating his position, Reagan narrowed his sights on Baby Doe.²⁰⁵ Although the infant had a much more complex medical diagnosis and prognosis than Reagan stated in his article, the former president blasted the Indiana Supreme Court ruling, stating the decision confirmed that Baby Doe's "retardation was the equivalent of a crime deserving the death penalty."²⁰⁶ Reagan noted:

The death of that tiny infant tore at the hearts of all Americans because the child was undeniably a live human being—one lying helpless before the eyes of the doctors and the eyes of the nation. The real issue for the court was *not* whether Baby Doe was a human being. The real issue was whether to protect the life of a human being who had Down[] syndrome, who would probably be mentally handicapped, but who needed a routine surgical procedure to unblock his esophagus and allow him to eat.²⁰⁷

President Reagan used the case of Baby Doe as a call to arms for members of Congress and his administration to preserve the sanctity of human life at every legislative opportunity.²⁰⁸ By his own words, President Reagan noted the intent behind the subsequently-promulgated Baby Doe regulations: "[t]he basic issue is whether to value and protect the lives of the handicapped, whether to recognize

204. *Id.*; see also PETER SINGER, RETHINKING LIFE AND DEATH: THE COLLAPSE OF OUR TRADITIONAL ETHICS 106 (1994) (quoting Reagan, *supra* note 198).

205. Reagan, *supra* note 199.

206. *Id.*

207. *Id.*

208. *Id.*

the sanctity of human life.”²⁰⁹ Reagan and his administration would spend the next several years attempting to make good on his statement.

B. Section 504 of the Rehabilitation Act of 1973

In the immediate aftermath of Baby Doe’s death, the Secretary of the United States Department of Health and Human Services (DHHS) wrote a letter to approximately 6,800 hospitals informing them that the agency was invoking Section 504 of the Rehabilitation Act of 1973, which stated, in part:

No otherwise qualified [handicapped] individual . . . shall, solely by reason of . . . his handicap, 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.²¹⁰

The section made it

[U]nlawful . . . for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) [t]he withholding [was] based on the fact that the infant is handicapped; and (2) the handicap [did] not render treatment or nutritional sustenance medically contraindicated.”²¹¹

Hospital noncompliance with the new interpretation of the civil rights law theoretically could result in loss of federal funds.²¹² In

209. *Id.*

210. 87 Stat. 394, 29 U.S.C. § 794(a) (1983).

211. Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers, 47 Fed. Reg. 26,027-02 (June 16, 1982).

212. *Id.*

announcing the policy, then DHHS Secretary Richard Schweiker said:

The President has instructed me to make absolutely clear to health care providers in this nation that federal law does not allow medical discrimination against handicapped infants.²¹³

In March 1983, DHHS revised its Interim Final Rule contemplating a “vigorous federal role,”²¹⁴ by requiring the conspicuous display of a notice in each delivery and maternity ward, pediatric ward, nursery, and intensive care nursery, indicating a toll-free “hotline” number that encouraged reporting of apparent discriminatory treatment to disabled newborns.²¹⁵ “When reports came in, ‘Baby Doe Squads’ . . . were dispatched to hospitals, demanding medical records” and investigating alleged mistreatment.²¹⁶ Officials from the DHHS were given authority to take “immediate remedial action” to protect the infant, and hospitals were required to provide access to their facilities, medical records, and personnel to investigators.²¹⁷

The Interim Final Rule, incorporating many of these policies and procedures, took effect on March 22, 1983, and was subsequently legally challenged by the American Hospital Association and others. The suit was brought against DHHS and its new secretary, Margaret Heckler, in the U.S. District Court for the Southern District of New York, to enjoin the enforcement of the Interim Final Rule.²¹⁸ Similar suit was brought by the AAP and other medical institutions against DHHS and Heckler in the District Court for the District of

213. *Around the Nation; U.S. Warns Hospitals On Care of Handicapped*, N.Y. TIMES, May 19, 1982, <http://www.nytimes.com/1982/05/19/us/around-the-nation-us-warns-hospitals-on-care-of-handicapped.html?sec=health>.

214. 48 Fed. Reg. 9,630 (Mar. 7, 1983).

215. See Annas, *supra* note 192, at 618.

216. See Robertson, *supra* note 5, at 33.

217. See Annas, *supra* note 192, at 618 (citing 48 Fed. Reg. 9,630 (Mar. 7, 1983)).

218. *Am. Hosp. Ass’n v. Heckler*, 585 F.Supp. 541 (S.D.N.Y. 1984). The New York lawsuit would be the basis for the United States Supreme Court’s subsequent decision in *Bowen v. Am. Hosp. Assoc.* discussed *infra* in Part V(D).

Columbia.²¹⁹ The District of Columbia court struck down and declared the Interim Final Rule “arbitrary and capricious and promulgated in violation of the Administrative Procedure Act.”²²⁰ District Judge Gerhard Gesell personally noted that the regulation’s primary purpose required “physicians treating newborns to take into account wholly medical risk-benefit considerations and to prevent parents from having any influence upon decisions as to whether further medical treatment is desirable.”²²¹ Without appealing the court’s ruling, DHHS revised the regulations and invited public comment.

“After the period for notice and comment had elapsed, [D]HHS, on December 30, 1983, promulgated the Final Rules and announced they would take effect on February 13, 1984.”²²² Although with slightly less sting than its predecessors, the Final Rules maintained the spirit of earlier drafts by requiring, among other things, federally assisted state child protective services agencies to utilize their “full authority pursuant to State law to prevent instances of medical neglect of handicapped infants.”²²³ Of importance to this Article, the Final Rules were not intended to apply to severely premature and low birth weight infants and parents; they only applied to:

(1) refusals to provide treatment or nourishment to handicapped infants whose parents have consented to, or requested, such treatment; and (2) the failure or refusal to take action to override a parental decision to withhold consent for medically beneficial treatment or nourishment.²²⁴

The guidelines stated that the hospital “may not ‘solely on the basis of the infant’s present or anticipated future mental or physical impairments, fail to follow applicable procedures on reporting such

219. *Am. Acad. of Pediatrics v. Heckler*, 561 F.Supp. 395 (D.D.C. 1983).

220. *Id.* at 400.

221. *Id.*; see also *Annas*, *supra* note 192, at 618.

222. See *Bowen*, 476 U.S. at 620.

223. 48 Fed. Reg. 30,849 (1983); *Bowen*, 476 U.S. at 610, 619.

224. *Bowen*, 476 U.S. at 615, n.4.

incidents to the child protective services agency or to seek judicial review.”²²⁵ After DHHS’s Interim Final Rule had been declared invalid in *Heckler* but prior to the Final Rules being promulgated in late 1983, a child with multiple birth defects was born in Long Island, New York.

C. *Baby Jane Doe*

On October 11, 1983, an infant known as Baby Jane Doe was born with multiple congenital defects including spina bifida, hydrocephalus, microcephaly, and other neurological defects in Long Island, New York.²²⁶ Without corrective surgery, the probability of her surviving more than a few weeks was unlikely.²²⁷ After consulting with her treating physicians, Baby Jane Doe’s parents decided to forgo surgery that was likely to prolong her life, but would not improve many of her other handicapping conditions.²²⁸ A Long Island resident, unrelated to the family, filed suit in Suffolk County Supreme Court, seeking the appointment of a guardian ad litem for the infant to demand the hospital perform the surgery.²²⁹ The trial court granted the relief requested by the guardian on October 20th, but was reversed the following day by the Appellate Division, which found that the “concededly concerned and loving parents” had “chosen one course of appropriate medical treatment over another” and made an informed decision that was “in the best interests of the infant.”²³⁰ Subsequently, the New York Court of Appeals affirmed.²³¹

While the state proceedings were ongoing, DHHS “received a complaint from a ‘private citizen’ that Baby Jane Doe was being discriminatorily denied” needed medical treatment and immediately referred the matter to the New York State Child Protective Service.²³²

225. *Id.* (quoting 45 C.F.R. Pt. 84, Appendix C, (a)(4) (1985)).

226. *See Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 588 (N.Y. App. Div. 1983).

227. *See id.*

228. *See Bowen*, 476 U.S. at 621.

229. *Weber*, 95 A.D.2d at 589.

230. *Id.*

231. *Weber v. Stony Brook Hosp.*, 456 N.E.2d 1186, 60 N.Y.2d 208 (1983) (*per curiam*).

232. *Bowen*, 476 U.S. at 621.

The agency investigated the medical neglect charge and concluded there was no cause for state intervention.²³³ At the same time, DHHS demanded the hospital make its medical records available for inspection in order to determine whether it was in compliance with Section 504 of the Rehabilitation Act.²³⁴ The hospital refused and the government subsequently filed suit in Federal District Court on November 2, 1983.²³⁵

The District Court in *United States v. University Hospital of the State University of New York at Stony Brook* ruled against the government, reasoning that the hospital had “at all times been willing to perform the surgical procedures in question, if only the parents . . . would consent.”²³⁶ Thus, the surgery was not denied because Baby Jane Doe was handicapped, but because her parents refused to consent to the procedure.²³⁷ The Court of Appeals affirmed noting: “[C]ongress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants when the statute was enacted”²³⁸ It thus rejected “the far-reaching position advanced by the government” and concluded that until Congress had spoken, “it would be an unwarranted exercise of judicial power to approve the type of investigation that . . . precipitated this lawsuit.”²³⁹ The government decided against filing a certiorari petition to the United States Supreme Court; instead, it sought judicial review from the high Court in the previously-decided *American Hospital Association v. Heckler*²⁴⁰ case in New York. That case, along with others, were consolidated into *Bowen v. American Hospital Association, et al.*²⁴¹

233. *Id.*

234. *Id.*

235. *See United States v. Univ. Hosp. of the State Univ. of N.Y. at Stony Brook*, 575 F.Supp. 607 (E.D.N.Y. 1983).

236. *Id.* at 614.

237. *Id.*

238. *United States v. Univ. Hosp. of the State Univ. of N.Y. at Stony Brook*, 729 F.2d 144, 161 (2d Cir. 1984).

239. *Id.*

240. 585 F. Supp. 541 (1984).

241. 476 U.S. 610 (1986).

D. Bowen v. American Hospital Association, et al.

A plurality of the United States Supreme Court in *Bowen v. American Hospital Association, et al.*,²⁴² expressed harsh criticism of the Reagan Administration's attempts to unilaterally make medical treatment decisions on behalf of disabled infants by noting the regulations interfered with parental rights to decide what was in a child's best interests.²⁴³ The Court noted how DHHS had changed its stance from once opposing parental rights in making medical treatment decisions on behalf of a disabled infant to embracing the concept. Justice Stevens wrote:

In the immediate aftermath of the . . . Baby Doe incident, the Secretary [of DHHS] apparently proceeded on the assumption that a hospital's statutory duty to provide treatment to handicapped infants was unaffected by the absence of parental consent. He has since abandoned that view . . . Indeed, it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent.²⁴⁴

Now that the Secretary had acknowledged requisite parental consent for a hospital to provide treatment to an infant, opined Justice Stevens, it was clear that the Final Rules "are not needed to prevent hospitals from denying treatment to handicapped infants."²⁴⁵ The Court's rationale in striking down the regulations was premised on the finding that the failure of DHHS to recognize that "withholding of consent by *parents* did not equate with discriminatory denial of treatment by *hospitals*," and thus, did not support the Secretary's claim that federal regulation is needed in order to prevent future Baby

242. 476 U.S. 610 (1986).

243. *Id.* at 632.

244. *Id.* at 630 (citation omitted).

245. *Id.* at 631 ("The Secretary's belated recognition of the effect of parental nonconsent is important, because the supposed need for federal monitoring of hospitals' treatment decisions rests *entirely* on instances in which parents have refused their consent.").

Doe and Baby Jane Doe cases.²⁴⁶ The Court concluded that the Secretary lacked the authority under section 504 to “dispense with the law’s focus on discrimination and instead to employ federal resources to save the lives of handicapped newborns, without regard to whether they are victims of discrimination by recipients of federal funds or not.”²⁴⁷ The Court went on to note that “[s]ection 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children.”²⁴⁸

As a result of the Court’s decision in *Bowen*, the Reagan Administration’s pro-life stance was undermined. The Administration turned to legislators to find an alternative route to preserve the sanctity of life.

E. The CAPTA Amendments: Baby Doe Rules Part II

In 1985, a Democrat controlled House and a Republican controlled Senate adopted a set of Baby Doe rules as amendments to the Child Abuse Prevention and Treatment Act (CAPTA).²⁴⁹ Understood primarily as federal funding requirements for states to receive monetary grants, the Child Abuse Amendments of 1984²⁵⁰ required states to establish policies and procedures for the reporting of and responding to medical neglect and by defining medical neglect to include the withholding of medically indicated treatment for a disabled infant with life-threatening conditions.²⁵¹ These regulations attempted to dictate medical treatment of extremely ill, premature, or terminally ill infants less than one year of age—requiring maximal treatment unless one of the following exceptions is met:

246. *Id.* at 632.

247. *Id.* at 611.

248. *Id.*; see also Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 798 (2005).

249. 42 U.S.C. §§ 5101–5107, 5118 (2006).

250. Pub. L. No. 98-457, 98 Stat. 1749 (1984).

251. *Id.*

- (1) [t]he infant is chronically and irreversibly comatose;
- (2) [t]reatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
- (3) [t]he provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.²⁵²

Determining the meaning of “chronically and irreversibly comatose,” “futile,” and “virtually futile” has proven difficult for clinicians and little guidance in interpreting the terms has been provided by the government. Whether “virtually futile” is narrowly interpreted to mean a one percent chance of survival or more liberally to mean a five percent chance of survival directly impacts a physician's medical decision-making.²⁵³ It is unclear from a reading of the rules. Additionally, “reasonable medical judgment” is narrowly defined only to allow application of the three exceptions; the definition does not allow parents and physicians to decide what is reasonable.²⁵⁴

Since their enactment, the amendments have brought both criticism and praise from medical and legal commentators alike. Some applauded the legal measure as a commitment to respecting human life regardless of disability.²⁵⁵ Others denounced the rules as being too distant from the reality of clinical decision making,²⁵⁶

252. See Kopelman, *supra* note 23, at 191; see also HHS Final Rules: Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to the Health Care for Handicapped Infants, 50 Fed. Reg. 14,888 (Apr. 15, 1985).

253. See Jon Tyson, *Evidence-Based Ethics and the Care of Premature Infants*, 5 LOW BIRTH WEIGHT 197, 200 (1995), available at http://www.futureofchildren.org/information2827/information_show.htm?doc_id=80057 (last visited Dec. 8, 2008).

254. See Kopelman, *supra* note 23, at 192.

255. See Robertson, *supra* note 5, at 34; see also *Mercy, Murder, & Morality*, HASTINGS CENTER REP., Nov./Dec., 1989.

256. Stanley J. Reiser, *Survival at What Cost? Origins and Effects of the Modern Controversy on Treating Severely Handicapped Newborns*, 11 J. HEALTH POL. POL'Y & L. 199, 209 (1986).

inconsistent with regulations affecting incompetent adults,²⁵⁷ or too dismissive of parental autonomy in making medical decisions on behalf of a child.²⁵⁸

Professor Loretta Kopelman and her colleagues surveyed United States neonatologists to determine whether the revised Baby Doe rules would affect their medical decision making in the NICU.²⁵⁹ Of the nearly 500 respondents, a majority of physicians felt the rules reduced parental rights to consent to or refuse treatment based on the infant's best interests.²⁶⁰ Approximately sixty percent of physicians believed the rules did not allow for adequate consideration of the infant's physical condition, i.e., its pain and suffering, and more than one-half of the respondents felt the infants would be overtreated when survival was improbable.²⁶¹ When asked a hypothetical question of whether the use of a respirator should be continued for a 550-gram infant who had developed seizures, a large hemorrhage in the brain, and had a five percent chance of survival with severe handicap, thirty percent of neonatologists felt the law *required* the continued use of the respirator, eighteen percent were uncertain, and twenty-three percent noted that the rules had changed their approach to such a scenario.²⁶²

Although uncertainty abounds among many neonatologists regarding how best to apply the Baby Doe rules to clinical practice, it is clear that "the norms of [neonatal] practice have shifted: physicians and hospitals [are] now more reluctant to defer automatically to parental wishes."²⁶³ Yet, many physicians resist this notion and refuse to alter their medical practice standards as a result of federal

257. Gary E. Jones, *Do the 'Baby Doe' Rules Discriminate Against Infants*, 17 PEDIATRICIAN 87, 91 (1990).

258. See Kopelman, *supra* note 23, at 191; Loretta M. Kopelman, Arthur E. Kopelman, & Thomas G. Irons, *Neonatologists Judge the 'Baby Doe' Regulations*, *supra* note 27; Veatch, *supra* note 180.

259. Loretta M. Kopelman, Arthur E. Kopelman, & Thomas G. Irons, *Neonatologists Judge the 'Baby Doe' Regulations*, *supra* note 27.

260. *Id.* at 677 (sixty-six percent of neonatologists believed the rules diminished parental autonomy).

261. *Id.* at 677, 679.

262. *Id.* at 678.

263. See Robertson, *supra* note 5, at 34.

coercion.²⁶⁴ For them, the Best Interests Standard remains intact; the standard permits families and physicians some latitude regarding what should be medically done even if the infant is neither comatose nor imminently dying.²⁶⁵

The first and only known judicial interpretation of the CAPTA Baby Doe rules was conducted in a Wisconsin's Appellate Court review of *Montalvo v. Borkovec*.²⁶⁶ The case concerned an extremely premature infant born at twenty-three weeks and three days of gestation, who was given maximal lifesaving treatments. The parents sued, claiming that their permission for these interventions was not sufficiently informed. The Wisconsin Appellate Court, however, stated: "[t]he implied choice of withholding treatment, proposed by the [parents], is exactly what CAPTA prohibits."²⁶⁷ The Court further restricted an interpretation of the Best Interests Standard, writing: "[i]n the absence of proof of a persistent vegetative state, our courts have never decided it is in the best interests of a patient to withhold or withdraw life-sustaining medical care."²⁶⁸

Some commentators note that the Wisconsin Appellate Court in *Montalvo* interpreted the CAPTA Baby Doe rules as the drafters intended: diminished parental autonomy, reduced consideration of infant suffering and future quality of life, and expanded use of NICU resources for infants with an improbable survival.²⁶⁹

Despite commentary from pro-life advocates and Baby Doe rule supporters stating the rules allow for reasonable and appropriate treatment choices, there appears to be widespread uncertainty and confusion in the medical community regarding the precise influence the rules should have on normative neonatal practice as evidenced by Kopelman's survey of neonatologists.

264. See Jason Morrow, *Making Mortal Decisions at the Beginning of Life: The Case of Impaired and Imperiled Infants*, 284:9 J. AM. MED. ASS'N 1146, 1147 (2000).

265. See Loretta M. Kopelman, *Baby Doe Rules: In Reply*, 116 PEDIATRICS 1602, 1602 (2005).

266. 647 N.W.2d 413 (2002).

267. *Id.* at 419.

268. *Id.* at 421.

269. See Tyson, *supra* note 253, at 200.

F. Impact of the Rules on Modern Medicine

As an opponent of the Baby Doe rules since their inception, ethicist Loretta Kopelman has written extensively on the subject.²⁷⁰ She notes that the AAP Committee on Bioethics believes many neonatologists have misunderstood these regulations in clinical practice.²⁷¹ The AAP advocates neonatologists employ a Best Interests Standard when making medical determinations on behalf of an imperiled newborn, and Kopelman notes that the committee believes the Baby Doe rules are not in contradiction to that standard.²⁷² Kopelman writes:

The committee claims that the Baby Doe rules allow considerable discretion and are consistent with individualized decision-making by clinicians and parents using the best-interests standard. This view is considered and rejected because these rules thwart individualized decision-making.²⁷³

Kopelman concludes that the committee is incorrect in its assumption, noting the rules do not allow the sort of discretion that they claim.²⁷⁴ The rules are only consistent with the Best Interests Standard if it is assumed, as it was by President Reagan, that providing maximal medical intervention to marginally-viable infants, regardless of the long-term consequences, is in their best interests.²⁷⁵

To date, the second set of Baby Doe rules remains legally unchallenged but they continue to be hotly debated in the medical and legal community. Some commentators state the rules are an appropriate and reasonable method to ensure proper medical decision

270. See Kopelman, *supra* note 23; Kopelman, *supra* note 265; Kopelman, *supra* note 248; sources cited *supra* note 27.

271. Kopelman, *supra* note 248, at 798.

272. *Id.* at 801.

273. *Id.* at 798. For the APP Committee's view, see American Academy of Pediatrics, Committee on Bioethics, *Ethics and the Care of Critically Ill Infants and Children*, 98 PEDIATRICS 149-53 (1996).

274. Kopelman, *supra* note 248, at 801.

275. See *id.*

making is conducted.²⁷⁶ Others disagree, stating the rules limit clinician and parental discretion to withhold or withdraw treatment deemed to not be in the best interests of the imperiled infant.²⁷⁷

President Reagan's ideal that every human being is valued equally is an admirable societal goal to be certain. But it is an ideal deeply flawed and virtually unattainable in today's society. It ignores the gray areas present in modern-day neonatal medicine where parents must decide between the death of a child and the choosing a life lacking meaningful human relationships, exorbitant financial assistance, and constant care. A premiere example is the case of Sidney Miller.

VI. SIDNEY MILLER: A CASE STUDY

Today, Sidney Miller is a teenager, yet she cannot walk, talk, feed herself, or sit up on her own.²⁷⁸ She is legally blind in one eye, and has a range of vision of only a few feet in the other.²⁷⁹ She suffers from cerebral palsy, seizures, and spastic quadriparesis in her limbs.²⁸⁰ She has severe mental retardation and will have the mental capacity of a six-year-old for the remainder of her life.²⁸¹ She has a surgically implanted shunt in her skull to drain fluid leaking from her brain.²⁸² And her mother, Karla, provides twenty-four hour care to change her diapers, feed and clothe her, and take care of her needs. Sidney's circumstances will never change. The Millers do not have the financial means to adequately cover the cost of Sidney's ongoing medical treatment.²⁸³ The hospital that delivered her refused to follow

276. See generally Thomas H. Murray, *The Final Anticlimactic Rule on Baby Doe*, HASTINGS CENTER REP., June, 1985, at 5-9; Robertson, *supra* note 5.

277. See Kopelman, *supra* note 248, at 798.

278. See Holly O'Neal Rumbaugh, *Miller v. HCA, Inc.: Disempowering Parents From Making Medical Treatment Decisions for Severely Premature Babies*, 41 Hous. L. Rev. 675, 696 (2004); see also *Miller v. HCA, Inc.*, 118 S.W.3d 758, 764 (Tex. 2003).

279. Rumbaugh, *supra* note 278, at 696.

280. *Id.*

281. *Id.*

282. *Id.*

283. See Rumbaugh, *supra* note 278, at 697.

her parents' requests that no heroic measures be taken to save her extremely premature life.

This Part of the Article details the premature birth of Sidney Miller and subsequently delivered medical treatment initiated over the objections of her father, Mark, as well as the resulting litigation leading to the Texas Supreme Court, as an example of conflict occurring between parents, physicians, hospital administration, and state and federal law.

A. Sidney's Birth

On August 17, 1990, Karla and Mark Miller presented themselves to the Woman's Hospital of Texas, in Houston, Texas, with Karla experiencing symptoms of premature labor.²⁸⁴ Karla was four months before her scheduled due date.²⁸⁵ An ultrasound revealed that Karla's fetus weighed approximately 629 grams, or slightly over one pound, and had a gestational age of about twenty-three weeks.²⁸⁶ Physicians immediately administered a drug to Karla to stop labor.²⁸⁷ Although her premature labor ceased, physicians subsequently discovered that Karla had an infection threatening to take her life and that of her unborn daughter.²⁸⁸ Karla's obstetrician, Mark Jacobs, M.D., and a neonatologist, Donald Kelley, M.D., informed Karla and Mark that if they had to induce delivery, the infant would have had little chance of being born alive.²⁸⁹ The physicians informed the couple that, even if born alive, the infant would most likely suffer severe impairments including brain hemorrhaging, blindness, lung disease, pulmonary infections, and mental retardation.²⁹⁰

After their discussion, Drs. Jacobs and Kelley asked the Millers to decide whether the newborn should be aggressively treated upon

284. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 761 (Tex. 2003).

285. *Id.*

286. *Id.*

287. *Id.*

288. *Id.*

289. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 761–62 (Tex. 2003).

290. *Id.* at 762.

delivery; at approximately noon that day, the Millers informed the physicians that “no heroic measures” were to be performed on the infant and instructed them to let “nature take its course.”²⁹¹ Dr. Kelley memorialized the Millers’ request in the medical record, and Dr. Jacobs informed other medical staff that no neonatologist would be needed at delivery.²⁹² Mark then left the hospital to make funeral arrangements for the infant.²⁹³

Alarmed by the notation in the medical record, the nursing staff notified other hospital personnel and administrators, and an afternoon of meetings ensued to discuss what should be done. Around 4:30 p.m. that afternoon, Mark was advised by Anna Summerfield, director of the NICU, that a hospital policy, as well as state and federal law, required the hospital to resuscitate any infant born weighing more than 500 grams.²⁹⁴ When Mark requested a copy of the policy, he learned that it was an unwritten policy.²⁹⁵ When asked by the Millers how they could prevent resuscitation and other measures from being taken on the newborn, hospital officials informed them that they would need to transfer Karla to another facility.²⁹⁶ However, Karla’s obstetrician had made it clear that transfer was not a viable option given Karla’s worsening condition.²⁹⁷

What concerned the physicians (as well as the hospital administrators) was the ethical dilemma of not providing any medical treatment without first observing the newborn’s condition.²⁹⁸ As Dr. Jacobs testified:

[W]hat we [an ad hoc hospital committee] finally decided that everyone wanted to do was to not make the call prior to the time

291. *Id.*

292. *Id.*

293. *Id.*

294. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 762 (Tex. 2003).

295. *Id.* (“Although Summerfield agreed that she said that, the only written Hospital policy produced described state law and did not mention anything related to requiring resuscitation to infants over 500 grams.”).

296. *Id.* at 763.

297. *Id.*

298. *Id.* at 762.

we actually saw the baby. Deliver the baby, because you see there was this [question] is the baby really 23 weeks, or is the baby further along, how big is the baby, what are we dealing with. We decided to let the neonatologist make the call by looking directly at the baby at birth.²⁹⁹

Mark refused to consent to resuscitation or other medical treatment be provided to the infant.³⁰⁰ Dr. Jacobs then noted in the medical record that a plan of evaluation would begin upon the birth of the newborn.³⁰¹

That evening, Karla's amniotic sac broke and physicians determined that labor would need to be induced to prevent further complications.³⁰² At 11:30 that night, Karla delivered a premature female infant weighing 615 grams, whom the Millers named Sidney.³⁰³ Sidney's gestational age was twenty-three and one-seventh weeks.³⁰⁴ The neonatologist, Eduardo Otero, M.D., noted that Sidney had a heart beat, "was blue in color and limp, gasped for air, spontaneously cried, and grimaced."³⁰⁵ The physician also noted that Sidney displayed no dysmorphic features other than being premature; he immediately "bagged" and "intubated" Sidney and placed her on ventilation.³⁰⁶ When asked at trial why, the physician responded:

Because this baby is alive and this is a baby that has a reasonable chance of living. And again, this is a baby that is not necessarily going to have problems later on. There are babies that survive at this gestational age that—with this birth weight, that later on go on and do well.³⁰⁷

299. *Id.*

300. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 763 (Tex. 2003).

301. *Id.*

302. *Id.*

303. *Id.*

304. *Id.*

305. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 763 (Tex. 2003).

306. *Id.*

307. *Id.*

Otero's testimony seemingly conflicted with the medical opinions previously given to the Millers before Sidney's birth. Neither Karla nor Mark objected at the time the treatment was administered by Otero.³⁰⁸

Sidney initially responded well to treatment, but within the first few days after birth, she suffered a brain hemorrhage—a common occurrence in extremely premature infants.³⁰⁹ It was unclear whether the hemorrhage resulted from the medical treatment provided or in spite of it.³¹⁰ Regardless, as predicted by her physicians, Sidney suffered severe physical and mental impairments that remain with her today.

B. The Lawsuit

Karla and Mark Miller sued the Woman's Hospital of Texas and its parent company, Hospital Corporation of America, Inc., and subsidiaries (collectively HCA, Inc.), asserting claims of battery and negligence.³¹¹ The Millers decided not to pursue legal action against any of the physicians, including neonatologist Eduardo Otero who performed the life-sustaining treatment.³¹² When asked by the media why they chose not to bring suit against the physicians, Mark Miller responded that he and Karla believed "the doctors just did what they were told" to do by hospital officials.³¹³ The physicians were involved in the litigation only to the extent that it was alleged they acted as the agents of the hospital, making the hospital legally responsible for their actions.³¹⁴

After approximately a one-month trial, the jury found that resuscitation had been performed on Sidney without the consent of the Millers and that the negligence of the hospital and HCA

308. *Id.*

309. *Id.*

310. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 763 (Tex. 2003).

311. *Id.* at 764.

312. *Id.*

313. See George J. Annas, *Extremely Preterm Birth and Parental Authority to Refuse Treatment—The Case of Sidney Miller*, 351 NEW ENG. J. MED. 2118, 2119 (2004).

314. See *Miller*, 118 S.W.3d at 764; see also Annas, *supra* note 313, at 2119.

“proximately caused the occurrence in question.”³¹⁵ Additionally, the jury concluded that both HCA and the hospital were grossly negligent, that the hospital acted with malice, and that Dr. Otero was the hospital’s agent in the resuscitation of Sidney.³¹⁶ The jury awarded the Millers \$29,400,000 in actual damages, \$17,503,066 in prejudgment interest, and \$13,500,000 in punitive damages.³¹⁷

C. The Appeal and Opinion of the Texas Supreme Court

The Texas Court of Appeals reversed the jury’s award.³¹⁸ The court concluded that, pursuant to state law, parents could withhold medical treatment from a child only if the child’s condition was deemed “terminal.”³¹⁹ But in Sidney’s case, the court noted, there was no “authority allowing a parent to withhold urgently-needed life-sustaining medical treatment from a non-terminally ill child.”³²⁰ Thus, according to the court, HCA and the hospital were under no duty to follow the Millers’ instruction to withhold resuscitation or to have a policy prohibiting resuscitation of newborns like Sidney without parental consent.³²¹ A lone dissenting justice disagreed with the majority and stated a court order was required to override the Millers’ decision and to determine what was in the best interests of Sidney.³²²

Upon appeal, the Texas Supreme Court concisely narrowed its role in the matter to “determin[ing] the respective roles that parents and healthcare providers play in deciding whether to treat an infant who is born alive but in distress and is so premature that, despite advancements in neonatal intensive care, has a largely uncertain

315. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 764 (Tex. 2003).

316. *Id.*

317. *Id.*

318. *Id.*

319. *Id.* at 764–65 (stating “the Natural Death Act [now the Texas Advance Directives Act] did not ‘impair or supersede any legal right . . . a person may have to [withhold] or [withdraw] life-sustaining treatment in a lawful manner’”) (quoting TEX. HEALTH & SAFETY CODE ANN. § 166.051); *see also* Annas, *supra* note 309, at 2119.

320. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 765 (Tex. 2003).

321. *Id.*; *accord* Annas, *supra* note 313, at 2119.

322. *Miller*, 118 S.W.3d at 765; Annas, *supra* note 313, at 2119.

prognosis.”³²³ After summarizing existing law that allowed parents the authority to make health care decisions on behalf of their children, the court noted that such parental autonomy has its limits. The court stated that the state punishes parents only for what amounts to child abuse or child neglect and that “as long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court.”³²⁴ Thus, absent evidence of abuse or neglect, a parent has the right to give or withhold consent for medical treatment for a child.³²⁵ However, the court went on to acknowledge that there may be times when physicians must act during which consent cannot be obtained from a parent.³²⁶ In those circumstances, the court explained the protocol:

A physician, who is confronted with emergent circumstances and provides life-sustaining treatment to a minor child, is not liable for not first obtaining consent from the parents . . . [This is] an exception to the general rule that a physician commits a battery by providing medical treatment without consent. As such, the exception is narrowly circumscribed and arises only in emergent circumstances when there is no time to consult the parents or seek court intervention³²⁷

In other words, physicians will not be legally liable for erring on the side of preservation of life in emergencies.³²⁸ In disagreeing with the Millers’ contention that Sidney’s birth was not an “emergent circumstance” and that there was plenty of time to seek a court order, the court concluded that the circumstances were unique, in that, a decision about resuscitation could not reasonably be made before birth. The court noted:

323. *Miller*, 118 S.W.3d at 766.

324. *Id.* at 767 (quoting *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 627 n.13 (1986)).

325. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 766–67 (Tex. 2003); *see also* Annas, *supra* note 313, at 2120.

326. *Miller*, 118 S.W.3d at 767.

327. *Id.* at 767–68.

328. *Id.* at 767–68; *see* Annas, *supra* note 313, at 2120.

The evidence established that Sidney could only be properly evaluated when she was born. Any decision the Millers made before Sidney's birth concerning her treatment at or after her birth would necessarily be based on speculation. [A decision made before birth] could not control whether the circumstances facing Dr. Otero were emergent because it would not have been a fully informed one according to the evidence in this case.³²⁹

The court held that the actions of Dr. Otero were not negligent because he was required to "make a split-second decision [and even though] the Millers were both present in the delivery room, there was simply no time to obtain their consent to treatment or to institute legal proceedings"³³⁰

Throughout the legal proceedings, HCA had consistently argued that the federal Baby Doe rules forbade any denial of medical treatment based on quality of life considerations.³³¹ The healthcare corporation argued that the rules were "scrupulously followed" and "faithful adherence to the public policy established by the regulations should not be thwarted through civil liability in damages"³³² While the court agreed in spirit, it went on to note that the rules required Texas to provide a mechanism by which the child protective services system could initiate legal proceedings to prevent the withholding of medical treatment from infants.³³³ But it was clear that neither the hospital nor HCA requested child protective services to initiate legal proceedings to override the Millers' decision to withhold treatment.³³⁴

The court affirmed the appellate court's judgment, declining to impose liability for battery or negligence on a physician for providing

329. *Miller*, 118 S.W.3d at 769.

330. *Id.*

331. *Id.* at 771.

332. *Id.*

333. *Id.*

334. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 771 (Tex. 2003).

life-sustaining treatment under emergent circumstances to an infant without parental consent.³³⁵

D. Implications of the Decision

George J. Annas, professor of law and bioethics since 1972, correctly notes that the Texas Supreme Court's decision limits physician discretion to the moments immediately after the birth of an infant.³³⁶ "More troubling," writes Annas, "the court implies that life is always preferable to death for a newborn and thus could be interpreted in the future to support the neonatologist who always resuscitates newborns, no matter how premature or how unlikely their survival may be without severe disabilities."³³⁷

The decision to resuscitate Sidney brought with it a new set of difficult decisions. While the court made it clear that after an initial emergency assessment by a physician at the time of delivery (with or without parental consent), parental consent for any subsequent medical treatment would be required.³³⁸ If refused or not provided, a health-care facility would need to pursue a court order.

Ethically, this requires a frank discussion with the parents about the health of and prognosis for their child, as well as trials of therapy that have realistic stopping points. Because there is a lack of uniformity nationwide regarding a clear approach to be used in cases like that of Sidney Miller, individual hospital policies and guidelines expressly delineating physician and parent roles in making reasonable medical decisions in the best interests of the infant may be the best we can do.³³⁹

Approximately one year before the Texas Supreme Court's decision in the *Miller* case, the United States Congress once again sought to fervently promote a sanctity of life preference through legislative means.

335. *Id.* at 772.

336. *See Annas, supra* note 313, at 2122–23.

337. *Id.* at 2121.

338. *Id.* at 2123.

339. *Id.*

VII. THE BORN-ALIVE INFANTS PROTECTION ACT OF 2002: A BABY DOE SEQUEL?

In 2002, Congress once again enacted legislation exhibiting a philosophical preference for the sanctity of life ethic by overriding any meaningful parental rights in making health-care decisions on behalf of a marginally-viable newborn, regardless of the child's long-term viability or quality-of-life concerns. The Born-Alive Infants Protection Act of 2002 (BAIPA),³⁴⁰ passed a Republican controlled House and a Democrat controlled Senate with very little political opposition, had the intent "to repudiate the flawed notion that a child's entitlement to the protections of the law is dependent upon whether the child's mother or others want him or her."³⁴¹ Understood by physicians to be an anti-abortion measure, there was very little initial concern regarding its passage; the medical community ultimately responded that the law would not alter normative medical practice.³⁴² However, since its enactment, BAIPA's reach has extended to infants born extremely premature via enforcement of Emergency Medical Treatment and Labor Act (EMTALA) regulations and the Child Abuse Prevention and Treatment Act (CAPTA).³⁴³ While the ultimate legal impact of the Act remains largely unknown, it is clear that BAIPA avoids any reference to medical standards of care, including the best interests of the infant, and does not specifically protect a parent's decision-making authority after delivery.³⁴⁴ Similar to the Baby Doe rules enacted during the Reagan Era, BAIPA continues a philosophical preference toward vitalism and preserving the sanctity of life at all costs.

This Part of the Article discusses the history and purpose behind BAIPA as well as the federal government's use of EMTALA

340. Pub. L. No. 107-207, 116 Stat. 926 (2002).

341. H.R. REP. NO. 107-186, at 3 (2001).

342. See Am. Acad. of Ped. Neonatal Resuscitation Prog. Steering Comm., *supra* note 14, at 681.

343. See Sadath A. Sayeed, *Baby Doe Redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A Cautionary Note on Normative Neonatal Practice*, 116 PEDIATRICS e576, e576 (2005).

344. *Id.* at e582.

regulations and CAPTA to enforce the Act's intent. It additionally discusses the Act's negation of parental decision-making power on behalf of an extremely premature or disabled newborn. Although the medical community dismisses BAIPA as inconsequential, this resulting oversight may ultimately lead to increased litigation between a physician required to resuscitate a marginally-viable infant and a parent who opposes such efforts.

A. History, Purpose, and Policy of BAIPA

The purpose of BAIPA was to establish that "infants who are born alive, at any stage of development (and regardless of the circumstances of their birth), are persons who are entitled to the protections of the law."³⁴⁵ To some degree, BAIPA was a legislative response to the United States Supreme Court's decision in *Stenberg v. Carhart*,³⁴⁶ overturning a state law that outlawed partial-birth abortion.³⁴⁷ The Act amended Title I of the United States Code by expanding the legal definition of "person," "human being," "child," or "individual," to include "every infant member of the species homo sapiens who is born alive at any stage of development."³⁴⁸ It also defined the term "person" to include "an infant who is completely expelled or extracted from his or her mother and who is alive, regardless of whether or not the infant's development is believed to be, or is in fact, sufficient to permit long-term survival, and regardless of whether the infant survived an abortion."³⁴⁹ An infant born alive is deemed, by the terms of the Act, as one who "displays any of several specific signs of life—breathing, a heartbeat, and/or definite movement of voluntary muscles."³⁵⁰ Thus, according to BAIPA's statutory language, an eighteen-week miscarried fetus with

345. Am. Acad. of Ped. Neonatal Resuscitation Prog. Steering Committee, *supra* note 14, at 680.

346. 530 U.S. 914 (2000).

347. *Id.* at 946; *see also* Sayeed, *supra* note 343, at e577.

348. Pub. L. No. 107-207, 116 Stat. 926 (2002).

349. Am. Acad. of Ped. Neonatal Resuscitation Prog. Steering Committee, *supra* note 14, at 680–81.

350. *Id.* at 681.

a detectable heartbeat after delivery is entitled to full protection under the law even though long-term survival is highly unlikely.³⁵¹

At the time of its passage, the few legislators who opposed the Act noted that it “does nothing” and “does not change existing law.”³⁵² Advocates of BAIPA as well as its congressional sponsors admitted that the legislation would not impose a new standard of medical care upon physicians nor change existing law.³⁵³ However, the law unequivocally alters the physician norm of deferring to parental discretion regarding the initiation or discontinuation of medical treatment for fragile newborns. In fact, the bill’s stated purpose was to repudiate the notion that parents should have decision-making power in those circumstances.³⁵⁴

After President George W. Bush signed BAIPA into law, the AAP Neonatal Resuscitation Program (NRP) Steering Committee issued an opinion stating that the law’s reach would not affect day-to-day neonatal medical practice and standards.

B. Response of the American Academy of Pediatrics

In March 2003, fewer than eight months after the passage of BAIPA, the AAP NRP Steering Committee issued an opinion regarding the law’s effects on normative neonatal medical practice.³⁵⁵ The Committee stated that although the Act contained “a great deal of rhetoric,” the “law does not proscribe medical care for newly born infants delivered at the limits of viability.”³⁵⁶ More specifically, the committee noted:

The debate regarding the efficacy of providing medical care to premature infants below a certain weight or gestational age is

351. See Sayeed, *supra* note 343, at e577.

352. H.R. REP. NO. 107-186, at 28 (2001) (statement of Rep. Melvin Watt at meeting of Committee on the Judiciary).

353. See Sayeed, *supra* note 89, at 601.

354. See Sayeed, *supra* note 343, at e578.

355. Am. Acad. of Ped. Neonatal Resuscitation Prog. Steering Comm., *supra* note 14, at 680–81.

356. *Id.* at 681.

clearly not relevant in the context of this law [BAIPA] should not in any way affect the approach that physicians currently follow with respect to the extremely premature infant. Physicians should discuss treatment options with parents, preferably before the birth of the infant.³⁵⁷

The Committee essentially dismissed the intent and purpose of the law with its statements.³⁵⁸ The Committee further noted the following:

At that point decisions about withholding or discontinuing medical treatment that is considered futile may be considered by the medical care providers in conjunction with the parents Those newly born infants who are deemed appropriate to not resuscitate or to have medical support withdrawn should be treated with dignity and respect, and provided with ‘comfort care’ measures.³⁵⁹

Thus, it could be said that the medical community responsible for treating extremely premature and disabled infants on a daily basis discounted the law as a symbolic gesture to affirm the sanctity of life, rather than as a substantive law altering neonatal practice. However, the AAP’s remarks and conclusions may have been premature. The Bush Administration subsequently dusted the cobwebs off BAIPA and began actively enforcing its terms under other federal laws.

C. BAIPA Transitions from Symbolic to Substantive Law

As BAIPA lay dormant for nearly two years, very little attention was paid to it. Then, in April 2005, the Secretary of DHHS announced that his agency would begin enforcing regulations impacted by the law through the EMTALA and CAPTA.³⁶⁰ Similar to the Reagan Administration’s policies after the passage of the Baby Doe rules, the Bush Administration’s resurrection of a dormant and

357. *Id.*

358. *Id.*

359. *Id.* at 681.

360. See Sayeed, *supra* note 343, at e576.

symbolic law threatened to greatly influence normative neonatal practice. The DHHS inter-agency memorandum detailing the relationship between BAIPA and EMTALA immediately set forth the agency's stance:

It has recently come to the agency's attention that there may be occasions where, in hospitals, an infant may be born alive within the meaning of the definition added to the U.S. Code by [BAIPA], but where hospitals have failed to comply with the requirements of EMTALA.³⁶¹

Under BAIPA, the DHHS interpreted EMTALA to protect all "born-alive" infants and stated it would actively investigate allegations of suspected violations whenever it found evidence that a newborn was not provided with at least a medical screening examination under circumstances in which a "prudent layperson observer" could conclude from the infant's "appearance or behavior" that it was "suffering from an emergency medical condition."³⁶² Thus, a family member could trigger an EMTALA investigation after observing the delivery of a twenty-week fetus who maintained a heartbeat for an hour before its death.³⁶³ When faced with such a scenario, most neonatologists would not consider it an emergency medical condition, but rather a medical situation requiring comfort care to be given to the infant and support given to the family.³⁶⁴ There is no flexibility under the Act's provisions for physician discretion, however; there is also no clear guidance whether screening examinations are required for all newborns regardless of survivability.³⁶⁵

361. Center for Medicaid & State Operations/Survey & Certification Group, *Interaction of the Emergency Medical Treatment and Labor Act (EMTALA) and the Born-Alive Infants Protection Act of 2002*, Baltimore, M.D., U.S. Dep't of Health & Human Servs., Centers for Medicare and Medicaid Servs., Ref: S&C-05-26, Apr. 22, 2005, available at <http://www.bricker.com/LegalServices/Practice/HCAre/laws/SCLetter05-26.pdf>.

362. See Sayeed, *supra* note 343, at e576.

363. *Id.*

364. *Id.*

365. *Id.*

In order to enforce its policies, the DHHS called on “individuals within health care facilities” to notify authorities when they suspected physicians were exceeding their authority by withholding medical treatment from newborns.³⁶⁶ But its real import may be the agency’s insistence on local execution of legal remedies to prevent nontreatment decisions deemed impermissible by the Baby Doe rules. The federal CAPTA rules “arguably remove quality-of-life considerations from the decision-making calculus and therefore may conflict with the best interests paradigm advocated by the American Academy of Pediatrics.”³⁶⁷

D. Possible Long-Term Impact of BAIPA

There is no question that BAIPA avoids any reference to the Best Interests Standard and actively dismisses parental involvement in decision-making after delivery.³⁶⁸ The reading of the law to require screening or resuscitation of a known nonviable born-alive infant clearly leads to absurd results; it also leads to potential disastrous long-term consequences if a marginally-viable infant is “saved” through medical intervention against the parent’s wishes and the child is so severely mentally and physically disabled as to have a nonexistent quality of life, profoundly impacting the family’s financial, emotional, and psychological well-being. Sidney Miller is a prime example of what can happen. Given that the expressed legislative intent of BAIPA was to ensure treatment is provided to infants clearly born before viability, judges will have to interpret the law accordingly, no matter how impractical the result.³⁶⁹ If, however, BAIPA ends up being read as only guaranteeing that all unfortunate, pre-viable newborns are treated “humanely,” and given appropriate palliative care, its efforts should be applauded.³⁷⁰

366. *Id.*

367. See Sayeed, *supra* note 343, at e576.

368. *Id.*

369. *Id.* at e582.

370. *Id.* at e584.

With President Obama at the helm of the United States, it is unlikely that the terms of BAIPA will be actively enforced at least for the next four years. A more prudent measure would be to urge a Democratically-led Congress to repeal the Act so little question remains regarding the proper method of decision making for marginally-viable infants: physician assessment of the infant's physical condition, conveying accurate diagnostic and prognostic information to parents, and active parental involvement in making a medical decision in the best interests of the infant.

VIII. RECOMMENDATIONS

In 1990, the editors of the *Harvard Law Review* published a comprehensive ethical and legal analysis on the matter of neonatal treatment decisions along with specific proposals on how to improve past policy mistakes.³⁷¹ The article's opening comments succinctly capture the locus of the debate:

Treatment decisions for severely handicapped and premature newborns are among the most disturbing and divisive of the legal and ethical dilemmas posed by increasingly sophisticated medical technologies. Because the paradigm of the rational, autonomous patient cannot apply to the newborn infant, the American legal tradition provides no definitive guidance on the issues of whether and when to withhold medical treatment. The birth of a severely handicapped or premature child thus forces society to choose between competing visions of what gives human life value and to determine the role of modern medical technology in that vision. Currently, decisions to withhold treatment from severely handicapped and premature infants are controlled by federal law; however, the federal standard has proved inadequate to address the complex issues surrounding

371. Harv. L. Rev. Assoc., *Medical Technology and the Law. IV. Neonatal Treatment Decisions*, in *Developments in the Law*, 103 HARV. L. REV. 1584 (1990).

such decisions. The controversy demands a more effective resolution.³⁷²

The editors' assessments of the practical and philosophical influences affecting normative neonatal practice were correct back then and they remain correct today. This Part of the Article offers practical and policy recommendations to reduce or remove medical decision-making conflict in the NICU on behalf of a marginally-viable newborn.

A. The Need for Parental Autonomy and Physician Discretion

Neonatologists and other physicians recognize that a NICU is a foreign world to most people.³⁷³ Though they spend their careers in the awe-inspiring unit, it is often a novel and jarring experience for parents—where hopes of health and happiness can be threatened by the birth of an extremely premature or disabled infant facing death.³⁷⁴ Parents often feel victimized, shocked, angry, and guilty.³⁷⁵ Thus, neonatologists should anticipate the vulnerability of parents, collaborate with them, and guide them through an often very difficult decision.³⁷⁶ The practical realities of the NICU require that parents and physicians be provided with some latitude in making medical determinations on behalf of a marginally-viable infant. However, with the current federal regulations in place, such discretion is significantly thwarted. A modified federal legislative posture allowing for such discretion would greatly enhance parent and physician ability to make medical determinations in the best interests of an imperiled newborn.

372. *Id.* at 1584.

373. Morrow, *supra* note 264, at 1147.

374. *Id.*

375. *Id.*

376. *Id.*

B. Procedural Safeguards

It is understood that parental ability to make such awesome life or death determinations may often be compromised by the stress, grief, and fear of making the wrong decision—whether it be death for a child or a severely handicapped life. Parents must live with the decision to let a child go or use emotional, financial, and other resources to sustain the child's poor quality of life. Under these conditions, parents may lack the rational ability to act in the child's best interests.

1. Effective Counseling

Neonatologists can provide parents with few guarantees regarding the future of a marginally-viable newborn. They can treat the newborn to the highest medical standards and use the latest in technology. Parents, on the other hand, have the agonizing role of watching helplessly at the infant's bedside. Thus, when physicians determine a medical course of action for an infant, it is best to actively include parents; when parents are excluded from the decision making process, their sense of helplessness may be increased.³⁷⁷

A 2005 study of the interaction between neonatologists and parents regarding infant intensive care found parents were reluctant to be actively involved in treatment decisions because they did not understand the complex medical information they received and were often fully unaware of the long-term implications of their decisions.³⁷⁸ The study found that most parents were young, bewildered, and had never before contemplated the possibility of what would be in their child's best interests—especially if serious complications occurred.³⁷⁹ Thus, a growing number of medical professionals are strongly encouraging the formulation of medical

377. *See id.* at 1147.

378. Joy H. Penticuff & Kristopher L. Arheart, *Effectiveness of an Intervention to Improve Parent-Professional Collaboration in Neonatal Intensive Care*, 19 J. PERINATAL & NEONATAL NURSING 187, 188 (2005).

379. *Id.*

staff guidelines to effectively counsel parents regarding the medical facts of the infant's case, treatment options, and supportive care to help them cope with difficult decisions.³⁸⁰

Before an infant's birth, the AAP and the American College of Obstetricians and Gynecologists recommend, at the very least, that pregnant women and their families be provided with an overview of the potential complications of extreme prematurity and should be informed of the range of survival and possibility of long-term neurodevelopmental disabilities.³⁸¹ For those with unexpected extremely premature births, parents and families should be treated with dignity and respect and supportively informed of the infant's full medical picture. If the situation warrants, physicians and medical staff should inform parents that palliative care may be the best course of action for a child. "When a decision is made to withhold resuscitation . . . or forgo other life-supporting treatments, the family should be treated with compassion, focusing on their needs."³⁸² When death is inevitable, hospital staff should allow time for parents to hold, touch, and interact with the infant before and after the infant dies; simple acts such as naming the child or obtaining a photograph, crib card, name band, or footprint sheet may give special meaning to the parents and should be offered.³⁸³ Clergy, supportive family, and counseling groups should similarly be made available to grieving parents and assessment of their emotional and psychological well-being should be conducted.³⁸⁴

Parental and medical discretion, however, should be limited to cases in which the value of treatment is truly unclear. Medical judgment should not demand continued treatment when there is no therapeutic benefit and when the infant's parents oppose such efforts.

380. See Kaempf et al., *supra* note 14, at 22; MacDonald et al., *supra* note 14, at 1024; Robin L. Pierucci et al., *End-of-Life Care for Neonates and Infants: The Experience and Effects of a Palliative Care Consultation Service*, 108 PEDIATRICS 653, 653 (2001).

381. See Kaempf et al., *supra* note 14, at 27; Am. College of Obstetricians & Gynecologists, *Perinatal Care at the Threshold of Viability*, 100 OBSTETRICS & GYNECOLOGY 617, 618 (2002).

382. See MacDonald et al., *supra* note 14, at 1026.

383. *Id.*

384. *Id.*

Similarly, physicians and health-care staff who are requested by a vitalist parent to continue a non-therapeutic course of treatment should be heard and afforded adequate due process protection.

2. Hospital Ethics Committees

Nearly all hospitals have an ethics committee or other panel to resolve difficult medical issues, such as the withdrawal of life-sustaining medical treatment for a marginally-viable infant. Typically, such committees are comprised of physicians, social workers, nurses, administrators, clergy, and even laypersons.³⁸⁵ As demonstrated by the cases of Sun Hudson and Emilio Gonzales, a hospital's ethics committee will examine the complete medical picture of the infant, opinions of the treating physicians, and those of the parents and family. The committee will offer recommendations and advice based upon the facts presented and may alternatively recommend other non-judicial mechanisms to provide an acceptable form of resolution for all parties.

3. Mediation Alternatives

The need for mediation may arise when a hospital ethics committee is unable to provide agreeable resolution to a particular conflict. The American Medical Association (AMA) and the AAP advocate mediation when disagreements arise.³⁸⁶ Because mediation is a non-judicial form of conflict resolution, it often employs therapy and morality to determine a just decision. The process is designed to overcome misunderstandings arising out of miscommunication and possibly quench escalating hostility between the parties allowing them to effectively communicate during an emotionally charged time. Parties must be willing to talk to one another, however, to reach an acceptable consensus. In some instances, that may be an impossibility. When the parties are unable or unwilling to agree, state

385. See Joanna M. Canter, *Nonjudicial Alternatives for Resolving End-of-Life Decisions for Minors*, 43 FAM. CT. REV. 527, 533 (2005).

386. *Id.* at 534.

law or judicial intervention may be necessary as a means of last resort.

C. Statutory Mechanisms

Used in the cases of Sun Hudson and Emilio Gonzales, the Texas Advance Directives Act³⁸⁷ provides a process-based mechanism to allow a hospital ethics committee to review cases when a physician refuses to honor a parent's demand that continued medical treatment be provided to an ailing newborn.³⁸⁸ The statute provides that if a committee agrees that continued life-sustaining treatment is inappropriate, "[t]he physician and health care facility are not obligated to provide life-sustaining treatment after the 10th day."³⁸⁹ Other provisions of the Act require the health-care facility to assist the parent in locating an alternative facility willing to accept the child.³⁹⁰ Judicial intervention in such cases is limited to granting an extension of the ten-day waiting period if a court finds, "by a preponderance of the evidence, that there is a reasonable expectation that a physician or health-care facility that will honor the patient's directive will be found if the time extension is granted."³⁹¹

Although the benefits and drawbacks of the state law have been discussed in length by legal scholars elsewhere,³⁹² the concept of such a mechanism is an attractive alternative to outright judicial decision-making to resolve conflict. Fashioning such a statute should be done with great care to ensure a proper balance between parental autonomy to make medical treatment decisions on behalf of a marginally-viable infant, physician discretion to determine that a

387. TEX. HEALTH & SAFETY CODE ANN. § 166 *et seq.* (Vernon 2007). In sum, the Act's statutory provisions set forth guidelines to be followed when a physician refuses to honor a treatment decision made by or on behalf of a patient and provides for transfer of the patient to another facility willing to accept him or her within a specified time.

388. *Id.* § 166.046.

389. *Id.* § (e).

390. *Id.* § 166.046(d).

391. *Id.* § 166.046(g).

392. See, e.g., Dahm, *supra* note 83; O'Callaghan, *supra* note 83; Zerwas, *supra* note 83; Halevy & McGuire, *supra* note 133; Lightfoot, *supra* note 120; Rumbaugh, *supra* note 278.

particular course of medical treatment is inappropriate, and an effective procedure to resolve the conflict between the two in an appropriate timeframe.

D. Judicial Intervention

Severely disabled and extremely premature infants have due process rights to adequate procedural protection in any decision to compel or withhold medical treatment based on state law.³⁹³ Accordingly, judicial review may be the avenue to resolve treatment disputes. However, when the judicial system intervenes, family privacy is undermined and a private matter is immediately thrust into the public domain for discussion via media outlets. The court system is largely unfamiliar with the particular facts and circumstances surrounding the infant's medical case and may ultimately make a decision that is not in the best interests of the child. Much legal scholarship has been devoted to exposing the inadequacies of the judicial system as a forum for resolving disputes regarding medical treatment.³⁹⁴ The AAP argues that such judicial intervention is only warranted as a last resort:

Recourse to the courts should be reserved for occasions when adjudication is clearly required by law or when concerned parties have disagreements that they cannot resolve, despite appropriate consultation, concerning matters of substantial importance.³⁹⁵

To best safeguard against the possibility of utilizing the judicial system to resolve medical treatment disputes, health-care facilities should develop policies and guidelines ensuring that effective counseling, care, and comfort are provided to parents in an effort to

393. See Harv. L. Rev. Assoc., *supra* note 371, at 1611.

394. See generally O'Callaghan, *supra* note 83; Martin L. Smith et al., *Texas Hospitals' Experience with the Texas Advance Directives Act*, 35 CRITICAL CARE MED., 1271 (2007); Canter, *supra* note 385.

395. See Canter, *supra* note 385, at 533.

maximize collaboration with treating physicians when making difficult medical treatment decisions in the best interests of the infant.

**CONCLUSION: CONSISTENT ASSESSMENT, CONTROL,
COLLABORATION, COUNSELING, CARE, AND COMFORT**

Given the deep moral and emotional turmoil impacting medical decision making on behalf of extremely premature infants grasping onto the edge of viability, it is clear that neonatologists and physicians in the NICU trenches daily largely dismiss a rigid federal policy in favor of parental collaboration when determining what is in the newborn's best interests. However, the Baby Doe debate rages on, looming like a dark cloud over many health-care facilities. True consensus is lacking among medical professionals nationwide regarding how best to deal with philosophical federal legislative initiatives favoring the sanctity of life over all other values. Legislating that human life is sacred and is to be preserved at all costs ignores a more complex set of philosophical, financial, and emotional concerns of the average parent when thinking about the future quality of life of his or her severely disabled child or for the physician treating a struggling newborn who only experiences pain.

Medical decision making for the marginally-viable infant will always be problematic for all parties involved. Complicating matters further are the impersonal, public federal policies being forced into an extremely private matter between parents and physician. The neonatal medical team should strive for accurate and dependable medical facts, and the parents should demand full and clear communication regarding those details. Physicians must continually assess the infant to provide the most complete and up-to-date medical picture to the parents and counsel them accordingly. Granted proper decision making authority, the parents, in collaboration with the physician's medical expertise and knowledge, must work together in evaluating the latest developments and complications of the infant's medical condition when making life or death determinations. It is proper to grant the parents some leeway in making these decisions.

However, there may come a point when, in the case of a parent's adamant vitalist belief, the physician's medical and ethical responsibility to the newborn may override parental demands. In such a case, health-care facilities must have policies and guidelines that adequately ensure a parent is heard—but also ensure medical treatment decisions are ultimately made in the best interests of the infant. Non-judicial intervention in most instances may be the best means of resolving the conflict.

Parents share their lives with their children. They interact, live, and learn from each other. The agonizing life or death choice a parent makes for his or her extremely premature infant in the small meeting room outside of the NICU not only dramatically impacts the infant's future quality of life, but the lives of the parents and family as well. It is not the legislator or the physician that must ultimately financially, emotionally, and physically care for a severely disabled infant with no hopes for real human interaction or relationships—it is the parents' responsibility. A federal or state policy dismissive of parental rights, instead favoring the sanctity of life in all circumstances, ignores this important fact. Philosopher Peter Singer eloquently and correctly stated the following:

If we put aside the obsolete and erroneous notion of the sanctity all human life, we may start to look at human life as it really is: at the equality of life that each human being has or can achieve. Then it will be possible to approach these difficult questions of life and death with the ethical sensitivity that each case demands.”³⁹⁶

The parents know their child's life is sacred, but they are also aware that the infant's likelihood (or lack thereof) of having meaningful relationships with others, experiencing joy and love, acquiring knowledge, and interacting with the world, is important to

396. Peter Singer, *The Quality of Life Is Most Important*, in *TERMINATING LIFE: CONFLICTING VALUES IN HEALTH CARE* 92, 95 (Gary E. McCuen & Therese Boucher eds., 1985).

human existence. Physicians must not forget this, nor should legislators.

