

STUDENT WORKS

I DIDN'T EVEN RAISE MY HAND: A MOTHER'S RETROSPECTIVE JOURNEY THROUGH END- OF-LIFE DECISIONMAKING AT THE "THRESHOLD OF VIABILITY"

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During an emotionally charged morning of speeches at a symposium entitled Reflections on and Implications of Schiavo, Dr. Jay Wolfson asked members of the audience to raise their hands if they had ever faced the difficult decision of giving or ceasing life-sustaining medical treatment for a loved one.¹ I watched as many members of the audience raised their hands. Later in the day, in a rush of guilt, I realized that the loss of my daughter, Madison Gerow, had indeed involved just such a decision, yet I had never considered her death from this perspective. Somehow, not raising my hand seemed an affront to Madison's memory.

Madison would be six now. On March 12, 1999, after several agonizing days of trying to stop the inevitable, Madison was born just shy of twenty-three weeks' gestation. She weighed one pound, four ounces, and measured only ten inches from head to toe. Born too early, and suffering from the initial effects of an infection that threatened to take both of our lives, Madison lived for approximately forty-five minutes. Except for a brief trip to the Neonatal Intensive Care Unit (NICU), Madison spent her short time on earth wrapped in the love of her parents and family.

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1. Jay Wolfson, Speech, *Reflections on and Implications of Schiavo* (Stetson U. College of L., Jan. 9, 2005). Dr. Wolfson was Terri Schiavo's court-appointed guardian ad litem.

*Is it wrong that I never thought of the decisions we faced at Madison's birth in the right-to-die context? Should the obstetricians or neonatologists have framed our decisions in terms of Madison's rights, or our rights, under the law? Should I have raised my hand?*²

I. INTRODUCTION

Quinlan.³ *Cruzan*.⁴ *Schiavo*.⁵ Each of these famed cases is known for the legal battles waged by parents regarding end-of-life decisions for their daughters—in the case of the first two, to forgo life support measures, and in the case of the third, to continue life support measures.⁶ *Schiavo*, the most recent of these cases to dominate the media, will likely be remembered more for renewing the national debate on right-to-die issues than for advancing the law.⁷ Since 1990, when the United States Supreme Court decided *Cruzan v. Director, Missouri Department of Health*, individuals, including incompetent adults via proxy decision-makers, have had a constitutional right to refuse medical intervention.⁸

However, there is a fundamental distinction between the decisionmaking process for babies born at the “threshold of viability” and the *Quinlan*, *Cruzan*, or *Schiavo* battles, which were each waged as an assertion of an incompetent *adult's* right to refuse or continue medical treatment.⁹ In cases involving premature ba-

2. In addition to Madison, the Author and her husband have three beautiful daughters—Morgan and Taylor, both thirteen, and Hannah, five, who is a gift to us all and a testament to the strength of optimism in the face of fear.

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

4. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990).

5. *In re Guardianship of Schiavo*, 851 So. 2d 182 (Fla. 2d Dist. App. 2003); George J. Annas, “Culture of Life” Politics at the Bedside—The Case of Terri Schiavo, 352 New Eng. J. Med. 1711, 1714 (Apr. 21, 2005) (discussing political intervention by the United States Congress, President George W. Bush, and Florida Governor Jeb Bush into the *Schiavo* case).

6. Annas, *supra* n. 5, at 1714; see Philip G. Peters, *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 Nw. U. L. Rev. 798, 799–801 (1997) (noting that a fundamental shift has occurred in these cases because in the early cases, the families argued against life-sustaining medical treatment, whereas in many of the more recent cases, it is the physicians who are arguing against the life-sustaining care in spite of opposition from the families).

7. Annas, *supra* n. 5, at 1711.

8. *Id.* Terri Schiavo's long struggle recently ended under the painful glare of intense media attention, bolstered by special-interest groups on each side. *Id.* at 1713–1714.

9. *Id.* at 1711–1713 (emphasis added). Karen Ann Quinlan, Nancy Cruzan, and Terri

bies, the battle is centered on parental rights of control in refusing or continuing life-sustaining medical treatment for their newborn infants.¹⁰ For adults, the right-to-die decision is one of retrospection—*what would they have wanted*; but for extremely premature babies, the decision is prospective—*what will their futures hold?*¹¹

Parents and medical professionals quietly make these decisions in NICUs and maternity wards across the country every day, but the decisionmaking process, including who controls the decision, varies widely between states and even from city to city, or hospital to hospital within the same jurisdiction.¹² As infant

Schiavo were each in their twenties when they were struck down by their injuries. *Id.* at 1711.

10. *Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients*, CEJA Report D-A-91, 1, 4, version later published as *Decisions near the End of Life*, 267 JAMA 2229 (1992) [hereinafter *Decisions to Forgo*] (noting that seriously ill newborns represent one end of the “life spectrum” of incompetent patients, while the elderly represent the other end, and that determining best interests for these two groups is “particularly complex”).

Various courts have upheld the individual right to forego life-sustaining medical treatment on the basis of three sources: 1) the common-law right to freedom from unwanted interference with bodily integrity, 2) the constitutional right to privacy or liberty, and 3) statute. However, it is generally recognized that the right to refuse life-sustaining treatment may, in rare cases, be outweighed by countervailing state interests.

Jeffrey T. Gorcyca, Health Systems Risk Review, *The Extremely Immature Newborn—The Dilemma of the Microbaby*, <http://www.pronational.com/news/hsriskrv/PreemieHS1Q2002.htm> (accessed Mar. 24, 2005).

11. *Decisions to Forgo*, *supra* n. 10, at 5 (emphasis added). The American Medical Association (AMA) notes, “Unlike the permanently unconscious patient, a newborn does not have previous interests, but does have clear present and future interests.” *Id.* However, determining present and future interests in neonatology “involves many uncertainties.” *Id.* “For example, in some circumstances there may be a good chance that heart surgery would extend a newborn’s life, but the surgery would have to be performed *without anesthesia* due to the immense stress that anesthesia can create on the infant’s system.” *Id.* (emphasis added).

The term “right-to-die” will be used broadly throughout this Essay in reference to end-of-life decisions, whether to continue or discontinue medical treatment. While decisions to continue treatment may be better termed right-to-life decisions, the thrust of this Essay is not about the politics of life and death decisions, but about how this process differs from the parallel decisions made for incompetent adults. See Annas, *supra* n. 5, at 1714 (criticizing political interference in the *Schiavo* case in defense of a “culture of life”).

12. Dana Wechsler Linden & Mia Wechsler Doron, *Eyes of Texas Fasten on Life, Death and the Premature Infant*, N.Y. Times F5 (Apr. 30, 2002) (highlighting the disparity in treatment philosophies between two prominent physicians in the field of neonatology: Dr. Marilee Allen, Assistant Director of Neonatology, Johns Hopkins School of Medicine, noting that decisionmaking should be shared and that she worries that intensive care increases suffering, versus Dr. Sheldon Korones, Director, Newborn Center, Memphis Regional

mortality rates rise in the United States and technological advances continue to push the point of viability to new horizons, the number of families facing these agonizing decisions will continue to increase.¹³ Although there is inconsistency in the decisionmaking process, some hospitals are getting it right.¹⁴ It is critical that existing medical protocols be uniformly implemented to ensure that these decisions can be made humanely and privately between parents and doctors, with the assistance of medical ethics committees when necessary, because if these cases reach the courts, the family's tragedy is compounded.

This Essay is a journey through the right-to-die decisionmaking process as it applies to babies at the "threshold of viability."¹⁵ In Part II, the Author explores the double-edged sword of technological advances with an overview of the challenges facing micro-preemies born at the "cusp" of survival.¹⁶ In Part III, the Author analyzes the current state of United States law relating to these right-to-die decisions to determine who has decisionmaking authority in withdrawing or withholding situations for newborns.¹⁷ In Part IV, the Author discusses potential solutions and best practices.¹⁸ And finally, in Part V, the Author will close with her personal reflections on this retrospective journey.¹⁹

Medical Center and Professor, University of Tennessee College of Medicine, noting that regardless of gestational age, "he continues life-sustaining measures until he is convinced that nothing can keep the baby alive").

13. Gorcyca, *supra* n. 10.

14. *Decisions to Forgo*, *supra* n. 10, at 7; Cal. Assn. of Neonatologists, *Guidelines for Neonates at the Threshold of Viability*, http://www.cansite.org/HTML_Files/Main/Policies/viability.html (accessed Mar. 24, 2005); Natl. Guideline Clearinghouse, *Perinatal Care at the Threshold of Viability*, [http://www.guideline.gov/search/perinatal care at threshold; select Perinatal care at the threshold of viability](http://www.guideline.gov/search/perinatal%20care%20at%20threshold/select%20Perinatal%20care%20at%20the%20threshold%20of%20viability) (accessed Mar. 25, 2005).

15. Harry Gee & Peter Dunn, British Assn. of Perinatal Med., *Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice*, <http://www.bapm.org/documents/publications/threshold.pdf>, 1 (July 2000) (noting that in 1993 the World Health Organization revised the "threshold of viability" for infants to between twenty-two and twenty-six weeks in developed countries, in recognition of neonatal advancements).

16. *Infra* pt. II (surveying the frequency of early preterm births and the resulting health challenges); Gorcyca, *supra* n. 10.

17. *Infra* pt. III (discussing the legal aspects of end-of-life decisionmaking for micro-preemies).

18. *Infra* pt. IV (exploring how this decisionmaking process should work).

19. *Infra* pt. V.

II. THE MICROPREEMIE AT THE "THRESHOLD OF VIABILITY"

During nursing care and treatments, Charlie would look up as if begging us to stop the pain, but his endotracheal tube prevented his cry from being heard.

. . .

Mary met us at the door of the funeral home. Charlie lay in a casket lined in blue and white ruffles. His face told us that he was now at peace, free from pain and machinery. And through my tears, I saw in his arms his little white teddy bear.²⁰

These are the words of a NICU nurse who tells a story that is repeated too frequently in NICU units throughout the country—Charlie, born at twenty-three weeks, struggled valiantly for almost four months through multiple complications, procedures, and surgeries, only to succumb just three days before he was finally to go home with his parents and siblings.²¹ While “miracle baby” stories make better headlines, Charlie’s story probably paints a more accurate picture of the battles faced by extremely premature infants.²²

In 2002, the infant mortality rate in the United States rose from 6.8 to 7 per 1,000 live births.²³ Although the increase may seem small, the Centers for Disease Control and Prevention (CDC) considered the increase significant because it marked the first step backward in infant mortality in the United States since 1958.²⁴ Approximately 400,000 babies are born prematurely in

20. Teresa M. Odell, *Tears for Charlie*, 34 *Nursing* 5, 5 (2004).

21. *Id.*

22. Elaine Monaghan, *Behold the World's Smallest Baby—Larger than Life (Go On, Put Your Hand over Her Nurse's Fingers and See)*, *The Times* (London) 28 (Dec. 22, 2004) (heralding the survival of Rumaisa, an Illinois baby born fourteen weeks early and weighing under ten ounces). While my husband and I believe we made the right decision for Madison, every time I see a story covering a miracle baby, my heart skips a beat as I think “what if.” In spite of my attempts to explain the rarity of survival for these babies, “miracle baby” stories have always been especially hard for our older girls, both six at the time of Madison’s death, to understand.

23. Betsy McKay, *Infant-Mortality Rise Is Tied to an Increase in Premature Births*, *Wall St. J. D4* (Jan. 25, 2005) (available at <http://www.pediatrics.org/cgi/content/full/110/5/1024/>).

24. *Id.* The initial analysis for the 2002 infant mortality rates, which were not released

the United States each year,²⁵ and of the 27,970 infant deaths in 2002,²⁶ forty-one percent were attributed to babies born at less than thirty-two weeks' gestation.²⁷ Of these, the highest death rates occur in babies born from twenty-two to twenty-five weeks' gestation, a range that the American Academy of Pediatrics (AAP) defines as the "threshold of viability."²⁸

Sometimes called "micropreemies," these babies face steep odds of survival from the start, and although cutting-edge technology gives them some chance of survival,²⁹ "an infant born at the threshold of viability presents a variety of complex medical, social, and ethical decisions."³⁰ Among the most difficult of these decisions is one to "withhold resuscitation, discontinue resuscitation, or forgo other life-support treatments."³¹

Born so small that their weight is measured in grams, not pounds, the survival rate for micropreemies born at the latter end of this range improves significantly;³² however, the likelihood of

until 2004, ties the rise in infant mortality to an increase in the number of babies born before thirty-two weeks' gestation. *Id.* Although there was speculation that the increase could be attributed to delayed motherhood and an increase in multiple births, the CDC's research did not support this finding. *Id.*

25. Gorcyca, *supra* n. 10. Internationally, the United States ranks a dismal twenty-eighth in the mortality rates of infants less than one year old. Editorial, *Too Many Babies Born Early Bloom Late, to Spare Premies a Childhood Filled with Disabilities, Ensure PreNatal Care*, Atlanta J.-Const. A10 (Jan. 18, 2005).

26. Cheryl Wetzstein, *U.S. Infant Death Rate Climbs for First Time in 40 Years*, Wash. Times A1 (Jan. 25, 2005) (noting that among the deaths contributing to the rise in infant mortality rates in 2002 were an additional 500 babies born weighing between one pound, one ounce and 10.5 ounces). "Modern medicine can sometimes save these tiny babies, but most die, often within a week." *Id.* The impact of these infant deaths cannot be underestimated because nearly half of the 54,000 children below age twenty who died in 2001 were infants under one. Karen Trotochaud, *End-of-life Decision Making for Children: Supporting the Needs of Parents*, <http://ethics.emory.edu/news/archives/000292.html> (accessed Mar. 24, 2005) (noting that the majority of the infant deaths were attributable to prematurity or congenital abnormalities).

27. McKay, *supra* n. 23.

28. Hugh MacDonald, *Perinatal Care at the Threshold of Viability*, 110 *Pediatrics* 1024, 1024 (2002).

29. Gorcyca, *supra* n. 10.

30. MacDonald, *supra* n. 28, at 1024. The ethical concerns cut both ways—on the one hand, there are concerns that no matter how hopeless the prognosis, aggressive treatments will be given as experimentation; on the other hand, there are concerns that it is impossible to determine in advance which babies can benefit from aggressive treatment. Gorcyca, *supra* n. 10, at 3.

31. MacDonald, *supra* n. 28, at 1026.

32. *Id.* at 1025. One pound equals 453.6 grams. Google Calculator, <http://www.google.com/help/features.html#calculator> (accessed Nov. 8, 2005). A baby born at twenty-three

moderate to severe disability does not improve at an equal rate. The rate of moderate to severe disability for these children, including blindness, deafness, cerebral palsy, mental retardation, learning disabilities, and behavioral problems, is fifty-six percent for babies born at twenty-three weeks' gestation, yet improves only to forty-six percent for babies born at twenty-five weeks.³³

Citing the *Textbook of Neonatal Resuscitation*, the AAP protocol recommends "noninitiation of resuscitation for newborns of less than twenty-three weeks' gestational age and/or 400 g[rams] in birth weight."³⁴ In underscoring the challenges involved in making these decisions, the AAP notes that "[e]ven relatively small discrepancies of [one] or [two] weeks in gestational age or 100 to 200 g[rams] in birth weight may have major implications for survival and long-term morbidity."³⁵ For this reason, the AAP stresses the importance of delaying the final determination of the withdrawing or withholding option until the baby is delivered so its actual weight and status can be accurately evaluated.³⁶ Because these decisions have profound long-term emotional, social, financial, and sometimes legal consequences, the AAP and many hospitals recommend an interdisciplinary approach to resolving these ethical dilemmas.³⁷ In spite of the existence of these thoughtful protocols, the approach to these decisions and the resulting outcomes vary significantly by location.³⁸

weeks' gestation has a thirty percent survival rate, while a baby born two weeks later has a seventy-six percent rate of survival; however, these rates are heavily dependent on the baby's weight, which can vary dramatically across gestational periods. MacDonald, *supra* n. 28, at 1026. A baby weighing between 401 and 500 grams at birth has only an eleven percent chance of survival, while a baby weighing in between 701 and 800 grams has a seventy-four percent chance of survival. *Id.*

33. *Id.* at 1024–1025.

34. *Id.* at 1026.

35. *Id.* at 1025.

36. *Id.* at 1026; see Jaideep Singh, John Lantos & William Meadow, *End-of-Life after Birth: Death and Dying in a Neonatal Intensive Care Unit*, 114 *Pediatrics* 1620 (2004) (hypothesizing that distinguishing between withdrawing and withholding decisions is important and would present a more accurate picture of "end-of-life [decisionmaking] in the NICU").

37. MacDonald, *supra* n. 28, at 1024–1025.

38. Stacey R. Walters, Student Author, *Life-Sustaining Medical Decisions Involving Children: Father Knows Best*, 15 *Thomas M. Cooley L. Rev.* 115, 116–117 (1998) (noting that consistent policies for treating premature babies are nonexistent and that decision-making control is driven by the hospital).

III. RIGHT TO DIE AT THE “THRESHOLD OF VIABILITY”

While the Schiavo drama was being played out in the United States, the plight of Baby Charlotte dominated the British media.³⁹ Baby Charlotte was five inches long and only one pound at birth; a year and a half later, her parents were embroiled in a legal battle against Charlotte’s doctors, who successfully obtained a do-not-resuscitate order through the courts.⁴⁰ In spite of the judge’s recognition that Charlotte’s “life could no longer be described as intolerable” because she has some ability to see, hear, and smile, and she “now responds to loud noises and tracks the movement of a colorful toy,” by deeming her a “terminally ill child” the judge allowed the do-not-resuscitate order to remain in place against her parents’ wishes.⁴¹ Court rulings against the parent’s wishes are possible in the United States as well.⁴²

A. Futility Cases Involving Micropreemies— A Gray Area of the Law

When there is clear and convincing evidence of an incompetent adult’s preference to withdraw or withhold life-sustaining

39. St. Petersburg Times, *British Court: Let Baby Die*, http://sptimes.com/2005/04/22/Worldandnation/British_court_let_ba.shtml (Apr. 22, 2005) [hereinafter *British Court: Let Baby Die*] (noting that “Charlotte was born in October 2003, six months into her mother’s pregnancy. She has had serious heart and lung problems, has never left the hospital and is fed through a tube and lives in an oxygen tent.”); see also James Cartledge, *Parents of Ill Baby to Continue Legal Fight*, Evening Mail (U.K.) 5 (Feb. 7, 2005); Richard Edwards, *Experts Divided over the Court’s Ruling on Charlotte*, Evening Stand. (U.K.) 7 (Oct. 8, 2004).

40. Cartledge, *supra* n. 39, at 5. The New England Journal of Medicine recently reported that in the Netherlands, where euthanasia has been legal for twenty years, doctors have extended the euthanasia process to infants under certain conditions. Peter Singer, *Pulling Back the Curtain on the Mercy Killing of Newborns*, L.A. Times B13 (Mar. 11, 2005); see also John Schwartz, *End-of-Life Decisions for Newborns*, http://www.iht.com/bin/print_ipub.php?file=/articles/2005/03/10/news/infant.html (accessed Mar. 24, 2005) (noting that one of the conditions identified for euthanasia in the Netherlands is the “most serious form of spina bifida” because it creates a life not worth living). This has outraged the Spina Bifida Association of America. *Id.* Douglas Sorocco, a lawyer and the Chairman of the Board of Directors of the association, noting that his condition might place him in the euthanasia category, said, “People with spina bifida are having families, and making a contribution to their communities. . . . I would say I have a life worth living. My wife would say I have a life worth living. My family would say I have a life worth living.” *Id.*

41. *British Court: Let Baby Die*, *supra* n. 39.

42. *E.g. Miller v. HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003) (holding that a doctor who provides life-sustaining treatment to a minor child without parental consent is not liable to the parents if the treatment was administered under “emergent circumstances”).

treatment, the law is clear.⁴³ However, for micropreemies, the decision centers on what is in the best interests of the baby.⁴⁴ Although both types of decisions generally fall under the umbrella of “futility” cases,⁴⁵ because the micropreemie decision involves controversial ethical and moral issues, the decision is fraught with ambiguity.⁴⁶ Depending on the jurisdiction, the breadth of these ambiguities may be surprising. The final decision-maker may be the parents or the physician; parents may be charged with neglect for insisting on aggressive care; or, parents may face criminal charges for implementing the withdrawing or withholding decision on their own.⁴⁷

Of course, as long as parents and physicians agree on what is in the best interests of the newborn baby and their decision is in line with hospital policy, interference by the courts is extremely unlikely. The ambiguities come to light when parents and physicians do not agree on the best interests of the newborn and one of the parties seeks a court order to enforce the continuation of life-sustaining care or the withdrawing or withholding decision, or when one of the parties takes unilateral action to enforce what they perceive at the time as the appropriate course of action.

43. Annas, *supra* n. 5, at 1711. Of course, the benefit of an advance directive is simply unavailable in the micropreemie situation.

44. *Decisions to Forgo*, *supra* n. 10, at 3 (“If there is no reasonable basis upon which to interpret what a previously competent patient would have decided, or if the patient never possessed decisionmaking capacity, the surrogate [decision-maker] should base treatment decisions on which outcome would most likely promote the patient’s well-being.”) The AMA lists the following factors for consideration in determining a patient’s best interests: the “expected duration of life with and without treatment, pain and suffering associated with the treatment, and the amount of incapacitation and ability to interact with others if life is sustained.” *Id.* at 3.

45. Peters, *supra* n. 6, at 799–801 (noting that disability rights laws that bind physicians and hospitals have resulted in “conflicting paradigms” for analyzing futility cases in the courts); Simon N. Whitney, *An Iconoclastic View of Medical Ethics*, 88 *Geo. L.J.* 713, 714–715 n. 7 (2000) (“‘Futility’ is a term of art in medical ethics. It refers to situations in which the physician feels that further treatment is useless or even harmful—futile—which leads to conflict if the family (or another third party) insists that treatment be continued.”).

46. Gorcyca, *supra* n. 10; Whitney, *supra* n. 45, at 717.

47. Peters, *supra* n. 6, at 804 (noting that parents may be charged with child neglect for insisting that physicians treat their newborns aggressively); Walters, *supra* n. 38, at 142–143 (noting that criminal prosecution of parents for withdrawing or withholding treatment is unusual but does occur occasionally).

B. Even So, Parents Generally Have the Power to Make Withdrawal Decisions

In the United States, it is clear that parents have broad discretionary power for making medical decisions for their newborns as long as their decision is in the best interests of the newborn.⁴⁸ However, because physicians and states may occasionally claim a valid constitutional interest of their own in the withdrawing or withholding decision,⁴⁹ parental decisionmaking power is not unlimited.⁵⁰ Although the United States Supreme Court has not ruled on this issue directly,⁵¹ in *Bowen v. American Hospital Assn.*,⁵² the Court recognized “that parental consent is paramount above federal or state power when it comes to treatment of the handicapped or premature newborn.”⁵³

As *Quinlan* and *Cruzan* are to persistent vegetative state cases, *Baby K*⁵⁴ is to the right of parental control for premature babies.⁵⁵ *Baby K* has been called “the most important futility case of the last century.”⁵⁶ Based on her religious beliefs, Baby K’s mother insisted on aggressive treatment for her newborn in spite of the fact that Baby K was born anencephalic.⁵⁷ The United States Court of Appeals for the Fourth Circuit Court affirmed the

48. Whitney, *supra* n. 45, at 716. This authority has been somewhat limited by the “1984 amendments to the Child Abuse Prevention and Treatment Act (CAPTA),” which may mandate treatment against the parents wishes in some situations. *Id.* at 717. “CAPTA appears to require aggressive treatment of almost all defective newborns, but provides a specific exception for infants (such as anencephalics) that are ‘chronically and irreversibly comatose.’” *Id.*

49. Walters, *supra* n. 38, at 124–126.

50. Gorcyca, *supra* n. 10. This broad discretionary power is based on the presumption “that parents act in the best interest[s] of their child.” Walters, *supra* n. 38, at 124.

51. *Id.* at 143.

52. 476 U.S. 610 (1986) (striking down the “Baby Doe” regulations that mandated treatment for handicapped newborns); Gorcyca, *supra* n. 10, at 4. This line of cases is relatively new for two reasons: (1) neonatal advancements have only recently expanded the threshold of viability for micropreemies, and (2) for most of the twentieth century, patients rarely questioned the physician’s decisionmaking authority. Whitney, *supra* n. 45, at 717–718.

53. Gorcyca, *supra* n. 10 (noting that absent parental consent, treatment of a newborn is actionable).

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

55. Whitney, *supra* n. 45, at 714–715.

56. *Id.* at 714.

57. *Id.* at 715 (noting that this care included ventilatory support in spite of physicians’ attempts to convince the mother that anencephalic babies are born without a higher brain and standard treatment is generally limited to “comfort care”).

trial judge's decision in favor of the mother's preference to continue treatment under the guise of the Emergency Treatment and Active Labor Act.⁵⁸ Some legal experts believe this case requires aggressive medical assistance for all anencephalic infants, but others argue that this rule only applies if parents demand aggressive treatment and they happen to reside in the Fourth Circuit.⁵⁹

C. However, Parental Decisionmaking Authority Has Its Limits

Every morning Karla Miller feeds her daughter, spooning or hand-feeding small bites into her mouth so she doesn't choke. She changes her diaper, washes and dresses her. Then Karla lifts the 50-pound 11-year-old into her wheelchair, where she sits, her limbs rigid and contorted, unable to see more than a few inches ahead of her, totally dependent on her parents or little brothers to push her to a special bus that takes her to school.

Sidney Miller attends school with her brothers, but she doesn't learn. She can't. "She is almost 12 years old and they believe she demonstrates the basic skills of a three-month-old. . . . She doesn't understand anything that's going on, though she does understand pain and suffering."⁶⁰

While *Baby K* reinforced the general rule that parents have the right to make withdrawing or withholding decisions for their newborns, other cases have set boundaries on parental decision-

58. *In re Baby K*, 16 F.3d at 598. *Baby K* is front and center in the ethical debate that continues to rage over the appropriateness of considering "quality-of-life" issues in withdrawing or withholding decisions. See Peters, *supra* n. 6, at 828-829 (noting that critics argue that quality-of-life judgments fail to treat "all lives with equal worth," and consider these judgments "morally improper, susceptible to abuse, and prohibited outright by anti-discrimination laws"). The AMA tackles the quality-of-life issue head-on by recognizing that quality-of-life issues will be considered, but defining quality-of-life as "worth to the individual whose life is in question, and not as a measure of social worth." *Decisions to Forgo*, *supra* n. 10, at 4.

59. Whitney, *supra* n. 45, at 717.

60. Traci Neal, *Who Has the Right to Decide When to Save the Sickest Babies?* <http://old.hartfordadvocate.com/articles/pullingtheplug.html> (accessed Mar. 18, 2005) (noting that ironically, Texas law, like most states, permits abortions as late as twenty-four weeks' gestation, yet the hospital indicated that they would call security if the father prevented assistance to the baby upon birth). The Millers contend that Sidney's resuscitation at birth, to which they did not consent, actually caused her brain damage and blindness. *Id.* Although the Millers disagreed with Sidney's initial resuscitation, they have since opted for life-saving measures on at least seven separate occasions. *Id.*

making authority.⁶¹ In *Miller v. HCA, Inc.*, the Supreme Court of Texas affirmed the appellate court's decision to overturn a \$42 million verdict in favor of the Millers.⁶² The Millers sued HCA (the hospital) for battery and negligence because the hospital's policy resulted in resuscitative treatment for their newborn daughter without parental consent.⁶³ Sidney, born at twenty-three weeks' gestation and weighing 615 grams, "although blue in color and limp, gasped for air, spontaneously cried, and grimaced" at birth.⁶⁴ Because Sidney was born alive with a "reasonable chance of living," the attending physician made an emergency decision to place her on ventilation.⁶⁵ The Court held that this action did not constitute battery or negligence because the "emergent circumstances" facing the attending physician at Sidney's birth provided an exception to the parental-consent rule.⁶⁶

In cases involving significant disagreement between parents and physicians, the desperate acts of parents have even led to criminal prosecution.⁶⁷ Although criminal prosecution in such cases is rare, Sammy Linares and Gregory Messenger both faced prosecution for taking unilateral steps to withdraw or withhold life-sustaining medical treatment from their children without agreement from the children's physicians or the authority of a court order.⁶⁸

When an Illinois hospital refused to disconnect Linares' six-month old son from life support even though he was in an irreversible coma, Linares kept the hospital staff at bay with a .357

61. *Miller*, 118 S.W.3d at 758; Gorcyca, *supra* n. 10, at 5 (noting that "at least two different state courts have ruled that the decision to withdraw life sustaining medical treatment must be based on competent, irrefutable medical evidence that the infant's condition is incurable and irreversible") (citing *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. 2d Dist. App. 1984), and *In re LHR*, 321 S.E.2d 716 (Ga. 1984)). *Miller* runs counter to the shift in futility cases, noted in the beginning of the Essay, of physicians asserting the withdrawing or withholding decision against the wishes of the parents. Peters, *supra* n. 6, at 799.

62. *Miller*, 118 S.W.3d at 772.

63. *Id.* at 761.

64. *Id.* at 763.

65. *Id.* Sidney's promise at birth, versus her resulting long-term condition, reflects the complexity of these decisions. There is no crystal ball to see what the future will hold for these babies, and as indicated by *Miller*, courts seem reluctant to judge the results using 20/20 hindsight.

66. *Id.* at 761.

67. Walters, *supra* n. 38, at 142-146.

68. *Id.* at 143-144.

magnum gun while he disconnected his son's tubes.⁶⁹ Linares held his son, who had choked on a balloon several months before, while he died.⁷⁰ Although Linares was charged with murder, he was not indicted by the grand jury.⁷¹

Dr. Gregory Messenger, a dermatologist, removed his extremely premature baby from a respirator so that the child could die in his mother's arms, rather than alone.⁷² The Messengers had issued a do-not-resuscitate order when their child was born, but she was put on a respirator anyway.⁷³ Dr. Messenger's case did make it past the grand jury, but he was acquitted at trial.⁷⁴

While these cases represent the extreme outcomes possible when communications break down between parents and physicians, they highlight the need to improve the decisionmaking process at the threshold of viability.

IV. HOW SHOULD THE NEONATAL DECISIONMAKING PROCESS WORK?

Facing the birth of a severely premature baby is extremely traumatic. When compounded by significant health risks to the mother, a common component in premature births, the level of stress faced by the parents and medical professionals is further magnified. Parents, physicians, hospital ethics committees, and courts can minimize the trauma by taking a lesson from the tragically famous incompetent adult end-of-life cases.

Although *Schiavo* did not advance right-to-die law, the case is a bleak reminder of the limitations of our judicial system—while the judicial system will eventually choose sides to resolve contested end-of-life cases, there are no winners, even when the family's wishes are ultimately supported by court order.⁷⁵ William

69. *Id.* Kimberlee K. Kovach, *Neonatology Life and Death Decisions: Can Mediation Help?* 28 Cap. U. L. Rev. 251, 251 (2000) (exploring the effectiveness of mediation in highly charged end-of-life situations). The liability-fearing hospital had told Linares that he would have to get a court order to remove his son's life support. *Id.* at 292.

70. Walters, *supra* n. 38, at 143–144.

71. *Id.* at 144.

72. *Id.* at 144–145 (citing *People v. Messenger*, No. 94-67694-FH (Mich. Cir. Ct. 30th Dist. Feb. 2, 1995)).

73. *Id.*

74. *Id.* (discussing the impact of jury nullification in these cases).

75. George Felos, the attorney who represented Michael Schiavo, commented that the judicial process had been so long and painful that no one in his or her right mind would

Colby, the attorney who represented the Cruzan family in the battle they ultimately won to remove their daughter's feeding tube, spoke these eloquent words during Joe Cruzan's eulogy in 1996:

The psychiatry books are filled with analyses that tell us that a parent who loses a child suffers the single greatest trauma a human being can experience. It is well documented that many parents never recover. But there is no book to tell us the depth of wound[s] suffered by a parent who loses a child to permanent coma, stays with that child night after night, year after year, and when recovery does not come, that parent must fight a highly public battle to free that child from unwanted medical technology—with the ultimate outcome, seven tortuous years after the accident, of “winning” the right to allow that child to die.⁷⁶

Even after a cursory review of these famed cases, most people would agree that the solution to end-of-life decisionmaking, whether for incompetent adults or micropreemies, lies *outside* of the courthouse. For incompetent adults, living wills or healthcare proxies provide a remarkably simple legal solution to prevent the immeasurable trauma that years of litigation bring to families like the Cruzans and Schiavos.⁷⁷

For micropreemies, however, there is no magic bullet with the legal power of a living will or healthcare proxy. Instead, physicians and hospital ethics committees sit second-seat to parents in determining the course of action that is in the best interests of the newborn. As a result, the solution for keeping micropreemie end-of-life decisionmaking outside of the courthouse does not lie in a legal document—it lies in communication and trust between the parents and physicians.

look to resolve disputes in end-of-life cases in the courts. George Felos, *Felos on Schiavo*, 35 Stetson L. Rev. 9, 13 (2005); see also William H. Colby, *Long Goodbye: The Deaths of Nancy Cruzan* (Hay House, Inc. 2002) (beginning and ending his account of the Nancy Cruzan story by noting that the tragedy did not end with Nancy Cruzan's death, because her father Joe, who plunged into depression after the legal battle was over, ultimately hung himself on his back porch six years later).

76. Colby, *supra* n. 75, at 397.

77. *Id.* at 419–420 (encouraging his readers to take the time to complete one of the documents).

Although the loss of a newborn is tragic no matter how the decisionmaking process is handled, the Hippocratic Oath⁷⁸ should serve as a guidepost to medical professionals to “do no harm” in guiding parents through the difficult decisionmaking process for their newborns. To “do no harm,” several steps should be taken to ensure that the parties involved can resolve these situations without judicial involvement. First, the thoughtful protocols already in existence in the medical community should be uniformly implemented in hospitals across the country. Second, the calls of several legal and medical experts for further collaboration and research into the decisionmaking process at the threshold of viability should be heeded. And third, resources for and the use of palliative and comfort care should be increased.

The AMA and the AAP already have excellent protocols in place for managing this decisionmaking process.⁷⁹ These protocols should be uniformly implemented to minimize the current inconsistencies between hospitals, and to foster increased communication and trust between parents, physicians, and hospitals.⁸⁰ The AMA recognizes parents as the preferred decision-makers for withdrawing or withholding decisions, but espouses a team-based approach for medical professionals to provide the information and support needed to make an appropriate decision.⁸¹

The AAP summarizes its protocol in the following five points:

78. For a translation of the original Hippocratic Oath, as well as several modern versions, see Pub. Broad. Serv., *The Hippocratic Oath Today: Meaningless Relic or Invaluable Moral Guide?*, <http://www.pbs.org/wgbh/nova/doctors/oath.today.html> (accessed Sept. 26, 2005) (noting that the Hippocratic Oath is one of the oldest binding documents in history, and that in the United States today, nearly all graduating medical students swear to a version of the oath).

79. *Decisions to Forgo*, *supra* n. 10; MacDonald, *supra* n. 28.

80. *Miller*, discussed *supra*, highlights the importance of communication between physicians and parents in making the withdrawing or withholding decision, especially regarding the importance of waiting until the baby is assessed at birth to make a final decision. In *Miller*, the parents and physicians were embroiled in a dispute before Sidney was even born. *Miller*, 118 S.W.3d at 762. The father actually left the hospital before the baby's birth to make funeral arrangements, but when the attending physician offered emergency life-sustaining care based on Sidney's better-than-expected condition at birth, neither parent voiced an objection. *Id.*

81. *Decisions to Forgo*, *supra* n. 10, at 7 (noting that “[h]ealth professionals are responsible not merely for attempting to communicate, but for ensuring that effective communication takes place”).

- (1) Decisions regarding all aspects of management of the birth and subsequent care of the infant are based on frequent reevaluations of the fetal/infant's condition and prognosis and are made jointly by the parents and the physicians;
- (2) Parents receive appropriate information about maternal risks associated with delivery options, potential for infant survival, and risks of adverse long-term outcomes;
- (3) Parental choice regarding management of the delivery and subsequent care of the infant is respected within the limits of medical feasibility and appropriateness;
- (4) Physicians become knowledgeable about contemporaneous local, referral center, and national comparative data regarding survival and long-term outcomes associated with extremely preterm birth; and
- (5) Future investigations of interventions in the management of extremely preterm delivery and/or subsequent care of the infant include evaluation of infant survival and long-term neurodevelopmental status as primary study outcomes.⁸²

In spite of the fact that infant death rates represent the lion's share of all childhood deaths, "[e]nd-of-life care for infants has undergone relatively little analytic evaluation."⁸³ Medical professionals calling for additional analysis on this topic have noted that although there have been "theoretical publications" about the best way to treat incurable infants, studies analyzing the actual care being provided to these infants is scarce.⁸⁴ The authors of *End-of-Life Care for Neonates and Infants: The Experience and Effects of a Palliative Care Consultation Service* note that the Institute of Medicine "states that a 'decent or good death is one that is: free from avoidable distress and suffering for patients, fami-

82. MacDonald, *supra* n. 28, at 1027.

83. Robin L. Pierucci, Russell S. Kirby & Steven R. Leuthner, *End-of-Life Care for Neonates and Infants: The Experience and Effects of a Palliative Care Consultation Service*, 108 *Pediatrics* 653, 653 (Sept. 2001) (noting that only two major medical studies have been completed on this topic since 1973).

84. *Id.*

lies, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."⁸⁵ These medical professionals have recently called for both quantitative and qualitative analyses of neonatal end-of-life decisions based upon this "framework of a good death" to determine the best treatments for newborns and families.⁸⁶

Medical ethicists recognize a need for more collaboration between the legal and medical fields regarding neonatal end-of-life decisionmaking.⁸⁷ Dr. James Childress, a professor of bioethics at the University of Virginia School of Medicine, has noted that high-publicity cases, like *Miller*, will likely increase the level of scrutiny and debate because "[t]his is an area that cries out for a lot more attention" and "[t]here's a failure of communication between doctors and lawyers and society. If we have that communication, who knows where we'll come out?"⁸⁸

Mediation may also enable parties to avoid deadlocks and court battles in these already difficult cases.⁸⁹ Kimberlee K. Kovach, Professor of Law at Texas University School of Law, calls for the medical, legal, and ethics professions to conduct an "earnest" analysis of mediation as a tool to resolve these disputes.⁹⁰ Professor Kovach points out that mediation has the potential to resolve these "problematic" interactions while simultaneously improving the level of trust between physicians and families, and avoiding the additional harm that conflicts in the decisionmaking process can do to parents.⁹¹

The AAP protocol for Perinatal Care at the Threshold of Viability recognizes the importance of providing "humane and compassionate" care when the withdrawing or withholding decision is made.⁹² The AAP indicates that in such situations, "comfort care" including "careful handling, maintaining warmth, avoidance of invasive procedures, and unobtrusive monitoring" should be pro-

85. *Id.* (quoting Inst. of Med., *Approaching Death: Improving Care at the End of Life* (Nat'l. Acad. Press 1997)).

86. *Id.*

87. Linden & Doron, *supra* n. 12.

88. *Id.*

89. Kovach, *supra* n. 69, at 291.

90. *Id.*

91. *Id.* at 292.

92. MacDonald, *supra* n. 28, at 1026.

vided.⁹³ The AAP also notes the significance of creating a setting that maintains dignity so that families can spend time with their dying infants, including after the newborns die.⁹⁴ Specifically, the protocol notes that “[s]imple personalizing acts, such as naming the infant; obtaining a photograph, footprint sheet, crib card, name band, or even a lock of hair; and recording birth weight and other measurements may be important to the parents and should be provided.”⁹⁵

At least one study has found that palliative care can improve end-of-life care for newborns.⁹⁶ *End-of-Life Care for Neonates and Infants: The Experience and Effects of a Palliative Care Consultation Service*, recently published in *Pediatrics*, reports the results of a four-year study of the impact of palliative care consultations on end-of-life care for infants.⁹⁷ The study analyzed 196 infant deaths at one Wisconsin hospital from 1994 through 1997.⁹⁸ The researchers found “1) the place of death to be more likely in a non-intensive care setting; 2) a higher incidence of withholding aggressive measures such as CPR, cardiac medications, mechanical ventilation, and other medical interventions; 3) no difference in the withdrawing of these medical measures; and 4) more frequent use of supportive care services” such as chaplains or social services.⁹⁹ The researchers further noted that these differences

93. *Id.*

94. *Id.*

95. *Id.* These suggestions probably sound terribly morbid to someone who has not experienced the loss of a newborn, but for me, photographs of Madison, and items such as her footprints, were and continue to be invaluable. These items are really all we have of our time with Madison, so we are thankful that our nurses took the time to safeguard these memories for us.

96. Pierucci, *supra* n. 83, at 656, 659. The Institute of Medicine differentiates palliative care from end-of-life care, noting that palliative care “works *with*—not *instead* of—other treatments.” Inst. of Med., *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families—Summary*, 2 (Marilyn J. Field & Richard E. Behrman eds., Natl. Acad. of Sci. 2003) (available at <http://www.nap.edu/catalog/10845.html>) (emphasis in original). The Institute includes the following in its definition of palliative care: pain relief, emotional and spiritual support, assistance in making decisions, giving truthful information, and respecting “choices, values, and cultural traditions” as palliative care, while it also includes decisions regarding life support, discussing last wishes, and grieving in end-of-life care. *Id.*

97. Pierucci, *supra* n. 83, at 654.

98. *Id.*

99. *Id.* at 659.

“demonstrate a better death” as defined by the Institute of Medicine, discussed in Part II above.¹⁰⁰

End-of-life decisionmaking for micropreemies would benefit significantly from a three-pronged approach consisting of implementation of consistent medical protocols, increased collaboration and research, and a commitment to palliative or comfort care in all neonatal units. While these situations will never be perfect or free from heartbreak, it is possible to avoid many of the devastating conflicts highlighted throughout this Essay.

*V. CLOSING: MAYBE I SHOULDN'T FEEL TOO GUILTY FOR
NOT RAISING MY HAND AFTER ALL*

As I embarked on this retrospective journey through end-of-life decisionmaking at the threshold of viability, I was apprehensive of what I might find. However, in completing the journey, I was reminded of what I already knew—Madison and I had excellent medical care delivered with compassion.¹⁰¹ Now, I also know that, in our case, the AMA and AAP protocols were followed to the letter.¹⁰² Everyone we came in contact with demonstrated a clear commitment to palliative and comfort care. Indeed, the small, thoughtful gestures of my doctors and the hospital staff got me through those first weeks and ensured peace of mind and the preservation of the all-too-brief memories for years to come.

Perhaps I didn't think to raise my hand because Madison died a “good death.”

100. *Id.* (referencing the National Institute of Health's “good death,” discussed *supra*, n. 83).

101. My obstetricians had safely delivered our twins at thirty-five weeks' gestation, six years earlier, so we trusted the medical team implicitly. Because our twins, born at 5.5 pounds and 4.9 pounds spent eight and ten days each in the NICU, we were also familiar with the NICU process.

102. Two neonatal consults were conducted in advance of Madison's birth. The grim statistics were discussed, and because we were already familiar with the NICU, we turned down the offer for my husband to visit the unit. However, based on Madison's anticipated weight and gestation, we did agree that heroic measures would not be taken. At birth, surprised by her size and initial condition, the doctors briefly sent Madison to the NICU. Unlike the Miller situation, this had been discussed in advance, so we supported this decision. I am not sure how long Madison was in the NICU—probably fifteen to twenty minutes. When she did not respond well to life-sustaining efforts, Madison was returned to the birthing room. She was baptized and remained with us, to be held, until she died.