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FOREWORD TO THE SYMPOSIUM

BABY DOE AT TWENTY-FIVE

Charity Scott*

The so-called Baby Doe Rules, which are federal laws defining “medical neglect” of newborns for states receiving federal funds for child abuse programs, remain controversial twenty five years after they were enacted. To explore their contemporary significance, Georgia State University’s College of Law, in partnership with Emory University’s Center for Ethics, hosted a law review symposium on February 9, 2009, that was entitled “The 25th Anniversary of the Baby Doe Rules: Perspectives from the Fields of Law, Health Care, Ethics, and Disability Policy.”¹ Nationally prominent professionals with expertise in neonatal medicine and decision-making in these diverse, interdisciplinary fields spent the day engaged in challenging debate and thoughtful reflection on these federal rules.

And yet the Rules have seemingly become dormant for many clinical practitioners who are actually caring for newborns in neonatal intensive care units across the country. Although physicians continue to struggle to help parents make good decisions for their seriously ill infants, just as they did when the Rules were first enacted, the Rules themselves apparently are not necessarily the primary tools that guide medical and parental decision-making about treatment in actual clinical practice today. Indeed, according to one of the speakers at the symposium, many of the younger, more recently trained neonatal physicians may not even have heard of the Baby Doe Rules.

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1. The symposium was supported in part by the generosity of The Greenwall Foundation and the Health Law Section of the State Bar of Georgia. The Georgia State University Law Review co-sponsored the symposium with the Center for Law, Health & Society at the College of Law.

This volume of the *Georgia State University Law Review* collects the essays of the symposium speakers. Several themes emerge from their engaging presentations and insightful scholarship. First, the normative standards for decision making remain as controversial today as they were when the Baby Doe Rules were enacted. Several authors note the Rules' origin in a right-to-life perspective of the Reagan administration, and that perspective continues to have advocates and critics today.

Second, advances in medical technology have made it possible to save the lives of infants who, twenty five years ago, could not have been saved. These advances mean that the kinds of cases posing difficult ethical challenges today tend to involve extremely premature infants whose prognosis both for survival and for future impairments is highly uncertain. This prognostic uncertainty complicates treatment decisions from both medical and policy perspectives. For example, how does one incorporate disability rights concerns, which prompted federal intervention in the first place in the 1980s and which were the focus of the first set of Baby Doe Rules, when the nature and extent of an infant's potential future disabilities are unknown? Third, the intellectual and practical debates today incorporate disagreements not only over what norms should be applied, but also over what processes should be used for resolving conflicts over treatment options for seriously ill or extremely premature infants.

The symposium offered the opportunity for speakers across a range of perspectives to reflect on the meaning and application of the Baby Doe Rules over past the 25 years. This Foreword provides a roadmap to the speakers' essays and an introduction to the complex issues in medicine, bioethics, law, and disability policy that the Baby Doe Rules continue to raise.

INTRODUCTION TO THE BABY DOE RULES

A highly publicized case involving the withholding of medical treatment from a baby with Down syndrome ("Baby Doe") in 1982 in Bloomington, Indiana, gave rise in 1984 to the federal law known as

the Baby Doe Rules, which went into effect the following year.² In the Indiana case, “Baby Doe” had a genetic anomaly known as Trisomy 21, which usually entails some degree of mental disability. He had an immediately life-threatening condition (a tracheo-esophageal fistula) that prevented his being able to be fed normally. With the concurrence of their obstetrician, the parents refused to authorize surgery to save Baby Doe’s life. Without the surgery, the baby died.

During the public controversy that followed, the Department of Health and Human Services promulgated regulations (the first set of so-called Baby Doe Rules) under the authority of Section 504 of the federal Rehabilitation Act of 1973.³ Interpreting the Act as prohibiting the denial of medical treatment to handicapped infants solely on the basis of their handicap by federally funded institutions, these administrative regulations encouraged hospitals to establish Infant Care Review Committees and required them to post “informational notices” delineating federal anti-discrimination laws as applied to handicapped newborns.⁴ The American Medical Association and other hospital and medical associations challenged these regulations, and ultimately the Supreme Court held them to be invalid.⁵

In the meantime, Congress promulgated another set of Baby Doe Rules, which were adopted as amendments to the federal Child Abuse Prevention and Treatment Act (CAPTA)⁶ and represented a negotiated compromise between the proponents and opponents of the first, antidiscrimination-focused regulations. This second set of Baby Doe Rules, also known as the Child Abuse Amendments of 1984,⁷ remains the law today, and was the subject of the symposium. These

2. Child Abuse Amendments of 1984, Pub.L. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101-5106i (2006) and implemented in relevant part by 45 C.F.R. § 1340.15 (2008)). For a reproduction of these Rules, *see* Appendix A.

3. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355 (1973).

4. 45 C.F.R. § 84.55; 49 F.R. 1622 (1984) (discussion of Final Rules).

5. *Bowen v. Am. Hosp. Assoc.*, 476 U.S. 610 (1986).

6. Pub.L. 93-247, Jan. 31, 1974, 88 Stat. 4.

7. Pub.L. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101-5106i (2006) and implemented in relevant part by 45 C.F.R. § 1340.15 (2008)).

rules condition the grant of federal funds for any state's child protective services program on the state's assurance that it can respond to reports of medical neglect, which may include the withholding of medical treatment from disabled infants with life-threatening conditions.

What do the Baby Doe Rules actually say?⁸ States receiving federal funds for their child welfare programs must have procedures for responding to reports of potential "medical neglect" of infants. As such, this federal mandate fits within a state's already-existing legal framework for responding to any potential case of child abuse or neglect, including medical neglect.

The Baby Doe Rules define "medical neglect" as including the "withholding of medically indicated treatment from disabled infants with life-threatening conditions."⁹ "Medically indicated treatment" includes treatment that in a physician's reasonable medical judgment would most likely be effective in "ameliorating or correcting" all of the infant's life-threatening conditions.

There are three exceptions when treatment is not medically indicated under the Rules.¹⁰ The first is when the infant is "chronically and irreversibly comatose." The second exception includes treatment that would "merely prolong dying"; would not be "effective" as previously defined; or would be "otherwise futile in terms of the survival of the infant." The third exception is when the provision of treatment "would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane." The failure to provide treatment to a seriously ill infant in any one of these three circumstances would not fall within the definition of "medical neglect" under the Baby Doe Rules.

What do the Baby Doe Rules really mean? Exploring this question is what much of the symposium was all about. The non-binding Interpretive Guidelines of the Department of Health and Human

8. See Appendix A to this Foreword.

9. 42 U.S.C. § 5106a(b)(2)(B) (2006).

10. *Id.* § g(6).

Services that accompanied the Rules state that they do “not sanction decisions based on subjective opinions about the future ‘quality-of-life’ of a retarded or disabled person.”¹¹ The disagreement between right to life advocates and advocates who urged taking quality-of-life concerns into consideration in treatment decisions for very ill infants was heated at the time the Rules were enacted,¹² and judging from the essays published for this symposium, remains equally controversial today.

Although Craig A. Conway was not a speaker at the symposium, his essay is included in this volume to provide readers unfamiliar with this field of law and ethics with an overview of the history of the Rules, the ethical and philosophical tensions in decision-making for extremely premature newborns (including the approaches based on “vitalism” and sanctity of life perspectives, and those based on “best interests” standards and quality-of-life concerns), and background to some of the case studies referred to by the authors collected in this volume, including the cases of Sidney Miller and Sun Hudson.¹³ In addition, a case scenario based on a draft by speaker Sadath A. Sayeed formed a backdrop to some of the discussions at the symposium, and is reproduced in Appendix B to this Foreword.

THE EVOLUTION OF NEONATAL MEDICINE IN THE AFTERMATH OF THE BABY DOE RULES

Mark R. Mercurio, Associate Professor of Pediatrics at Yale University School of Medicine and Director of the Yale Pediatric Ethics Program, opened the symposium with a thorough review of the evolution of ethical perspectives, technological advances, and

11. 45 C.F.R. Pt. 1340 Appendix. These Guidelines also provide that even if an exception applies, “the infant must nonetheless be provided with appropriate nutrition, hydration, and medication.”

12. Compare James Bopp, Jr., and Thomas J. Balch, “The Child Abuse Amendments of 1984 and Their Implementing Regulations: A Summary,” 1 ISSUES L. & MED. 91, 114–19 (1985) with Nancy K. Rhoden, “Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts,” 58 S. CAL. L. REV. 1283, 1313–33 (1985).

13. Craig A. Conway, “Baby Doe and Beyond: Examining the Practical and Philosophical Influences Impacting Medical Decision Making on Behalf of Marginally-Viable Newborns,” 25 GA. ST. U. L. REV. 1097 (2009).

clinical practice in newborn intensive care since the Rules were promulgated.¹⁴ His insightful essay reflects the French saying, “plus ça change, plus c’est la même chose.”¹⁵ While there have been significant changes in both the technology of neonatal treatments and the attitudes of neonatologists and parents over the years, the fundamental questions surrounding the care of seriously ill infants remain the same.

What has changed? According to Mercurio, there are now more premature and other seriously ill babies to care for, more specialty-trained neonatologists and neonatal intensive care units (NICUs) to care for them, and more options for their treatment. Technological advances in prenatal diagnosis mean fewer surprises at delivery, in part due to more pregnancy terminations after a prenatal diagnosis of severe fetal anomalies. Advances in assisted reproductive technology mean more multiple-gestation newborns, with corresponding complications for their care. Technology today can be offered to extremely premature infants who years ago would have been thought too young to survive. Surgery and other treatments that were not offered years ago for certain conditions (such as hypoplastic left heart syndrome and Trisomy 13) are now offered and in some cases encouraged or even considered obligatory. Most recently in 2008, a neonatal calculator can now gauge with much improved accuracy the statistical chances of survival with and without physical or neurological impairments for extremely premature infants, based on data collected on thousands of neonates at numerous NICUs across the country.¹⁶

What has not changed is the central question over treatment: How low must the odds of survival be, or how severe must the burdens of treatment be, to justify allowing parents to refuse medical treatment

14. Mark R. Mercurio, *The Aftermath of Baby Doe and the Evolution of Newborn Intensive Care*, 25 GA. ST. U. L. REV. 835 (2009).

15. “The more things change, the more they stay the same.”

16. See National Institute of Child Health and Human Development, NICHD Neonatal Research Network (NRN): Extremely Preterm Birth Outcome Data, available at http://www.nichd.nih.gov/about/org/cdbpm/pp/prog_epbo/epbo_case.cfm (last visited Apr. 25, 2009).

for their infant?¹⁷ The line between viable and non-viable births may have been pushed back over the years to fewer weeks of gestation and lower birthweights, but that simply changes the point along the continuum at which the central question gets raised: Should treatment be optional, required, or not offered for parents whose infant is born at twenty-one or twenty-two or twenty-three weeks' gestation? At 400 or 450 or 500 grams? What has also not changed is whether considerations beyond those affecting only the infant should be taken into account when deciding whether non-treatment is an option, such as burdens on the infants' parents or siblings, or cost considerations in long-term care.

Mercurio acknowledges that the attitudes of physicians and parents have changed over the years. At his NICU today, for example, parents of a Down syndrome baby with a condition similar to the original Baby Doe would not be permitted to refuse the same life-saving surgical repair; a court order to overturn that parental decision would be sought and almost certainly obtained today.¹⁸ He also observes that more common today than parental refusals of treatment of arguably appropriate care are parental demands for arguably inappropriate care. Rather than eliminate the hard cases, however, such changes have simply shifted which cases are appropriate for the hard moral work—to determine when the degree of burden to the infant, including the severity of prognosis and anticipated disability, justify non-treatment.¹⁹

THE BABY DOE RULES AND THE ACTUAL PRACTICE OF NEONATAL MEDICINE

Several authors suggest that the Baby Doe Rules, despite the controversy generated by them in the ethical, medical, and legal literature over the years, have not had a major impact on the actual practice of neonatal medicine. Sadath A. Sayeed, a faculty member at

17. Mercurio, *supra* note 14, at 844.

18. *Id.* at 848, 855.

19. *Id.* at 855.

Harvard Medical School and a member of the Ethics Committee at Children's Hospital Boston, acknowledges that it is unclear what practical effect the Rules have had on actual clinical decision-making, and suggests that they have not substantially changed long-standing normative practices.²⁰ In his essay, Sayeed examines closely the moral intuitions that underlie the Rules and the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research which preceded them.²¹ He argues that the President's Commission supports an ethical conclusion that exceedingly few newborns who have a chance at survival should be denied a trial of medical treatment. Sayeed goes on to assert that this controversial conclusion challenges a widely accepted professional norm of recommending against treatment for newborns of doubtful viability.²²

Sayeed begins with a thorough examination of the President's Commission's ethical framework, with its emphasis on the Best Interests Standard for decision-making. The Commission emphasized that determining the best interests of the infant requires a very restrictive balancing of the benefits and burdens of treatment, such that treatment is denied only where continued survival would not be of "net benefit" to the infant. Only the infant's own perspective is relevant in this balancing, according to the Commission, not the perspectives of the parents or others. Very few cases should be truly ambiguous in the Commission's view; in most cases it should be clear that treatment is either beneficial (and thus obligatory) or futile (and thus not required).²³

Sayeed then applies the Commission's ethical framework to actual clinical practice involving cases of doubtful viability, where long-term survival odds are low and the likelihood of significant impairments in infants who do survive is high. He provides in-depth

20. Sadath A. Sayeed, "A Meditation on Newborns Who Need Medical Treatment to Survive," 25 GA. ST. U. L. REV. 865, 874, 893 (2009).

21. *Id.* at 866.

22. *Id.*

23. *Id.* at 867.

analysis of recent empirical literature which suggests that, in professional practice, providers may be making treatment decisions on the basis of categorical rather than individualized assessments of the potential for survival (for instance, not to offer treatment below twenty-three weeks' gestation). Not only did the Commission recommend against such across-the-board thresholds, but their use can become a self-fulfilling prophecy of the predicted low chances of survival.²⁴ Moreover, the data provide wide statistical variations in survival which belie any categorical presumption that treatment is "futile" in certain cases.

According to Sayeed, actual provider decision-making regarding treatment is thus likely informed not just by survival chances, but by predicted quality-of-life concerns as well.²⁵ He poses the question whether professional decision-making involving infants whose viability is doubtful should focus more transparently on taking advantage of small but real chances of survival, and less implicitly on uncertain predictions of quality-of-life after survival. This approach, he argues, would be consistent with the ethical underpinnings of the President's Commission and the Baby Doe Rules.²⁶ He concludes his thoughtful and thought-provoking essay with another call for transparency in clinical decision-making. Although rejected by the Commission as permissible factors in decision-making for seriously ill newborns, concerns about the burden on parents and siblings and the economic costs of aggressively treating infants of doubtful viability in order to achieve their survival should be openly acknowledged. These concerns may not ultimately trump newborn survival interests, according to Sayeed, but they should be part of the ethical analysis and societal debate.

Jatinder Bhatia, Professor and Chief of the Neonatology Section of the Pediatrics Department of the Medical College of Georgia, also suggests in his essay that the Baby Doe Rules do not have a

24. *Id.* at 876.

25. *Id.* at 882.

26. *Id.* at 891.

significant impact on clinical practice today.²⁷ In his presentation at the symposium, he observed from his personal experience that neonatal practitioners in the current generation may not even be aware of the Rules.

Bhatia focuses on the importance of palliative care for a newborn for whom aggressive treatment will not, or will no longer, be provided. He suggests that there are three primary circumstances in which palliative care should be considered: (1) when a neonate is at the limit of viability; (2) when a neonate has a lethal congenital anomaly (such as anencephaly or Trisomy 13); and (3) when a neonate has a serious condition that has not responded to maximum medical or surgical treatment.²⁸

Bhatia emphasizes the central role of parents in the decision to initiate palliative care, which focuses on relief from pain for the infant, warmth and comfort, privacy, and dignity after a decision to withhold or discontinue aggressive therapy. Although he recognizes that quality-of-life considerations are controversial under the Baby Doe Rules, he suggests that they need to be considered in counseling parents, who themselves need to be supported during the infant's therapy and their decision-making process. He makes a critical distinction between withdrawing therapy and not withholding care. Even though a decision has been made to not offer, or to discontinue, intensive therapy, the family should not experience that decision as the termination or withholding of care. Hospice care should be explored with the family, and palliative care—which embraces physical, emotional, and spiritual dimensions of caring for the infant—should always be offered to enhance the quality of the infant's remaining life.²⁹

If it is true as a matter of clinical reality, as Sayeed and Bhatia suggest, that contemporary practitioners work in clinical settings largely unaffected by a strict interpretation or application of the Baby

27. Jatinder Bhatia, "Baby Doe: Does It Really Apply Now? Palliative Care of the Ill Neonate," 25 GA. ST. U. L. REV. 901, 908 (2009).

28. *Id.* at 904.

29. *Id.* at 904, 905.

Doe Rules, then other options are available to align the law more closely with contemporary neonatal practice: society could encourage stricter adherence to the Rules (a course favored by author Thomas J. Balch, discussed *infra* under *Process*), or society could reject them in favor of another standard of care more in line with actual practice (a course favored by author Loretta M. Kopelman, in the next section).

CRITERIA: BY WHAT STANDARDS SHOULD DECISIONS INVOLVING
SERIOUSLY ILL INFANTS BE MADE?

Loretta M. Kopelman, Professor of Medical Humanities and founding Chair of the Department of Medical Humanities at the Brody School of Medicine at East Carolina University, argues that the Baby Doe Rules should simply be rejected and that the Best Interests Standard should govern treatment decisions for newborns, just as that standard governs all other decisions affecting children.³⁰ Kopelman acknowledges that some professional groups, like the American Academy of Pediatrics, have taken the position that the Baby Doe Rules do reflect the Best Interests Standard and do not inhibit reasonable medical judgment or substitute an alternative standard of care for infants under one year of age; for these professional groups, the Baby Doe Rules exist compatibly with current medical practice and standards of care.³¹ She disagrees, arguing that this interpretation is unsupported by the literal text of the Rules which she finds inflexible, requiring maximal life-saving treatment unless an infant is dying or comatose and allowing decision makers no discretion to switch to a palliative course of treatment to relieve a very sick infant's pain and suffering. She argues that the Baby Doe Rules, by their terms, allow pain and suffering to be considered in choosing a course of care only if treatment is virtually futile in terms of survival—in other words, only if the infant will die despite the treatment.

30. Loretta M. Kopelman, "Why the CAPTA's Baby Doe Rules Should Be Rejected in Favor of the Best Interests Standard," 25 GA. ST. U. L. REV. 909 (2009).

31. *Id.* at 912, 913.

Her primary criticism of the Baby Doe Rules centers on what she views as its deviation from the legal and ethical standard for surrogate decision-making involving all other incompetent patients, whether children or adults—namely, the Best Interests Standard. According to Kopelman, the Best Interests Standard permits flexible, individualized decision-making weighing the benefits against the burdens of treatment, and it allows a surrogate to choose comfort care rather than life-prolonging treatment for a patient who is experiencing pain and suffering.³² She observes that the President's Council on Bioethics takes this kind of individualized best interests approach for incapacitated adult patients without an advance directive. By way of example, she notes that the Council would consider renal dialysis an optional treatment for an Alzheimer's patient who became agitated and confused by being subjected to it three times a week, even though the patient would quickly die without it. She argues that the same principle should be applied to a seriously ill infant in intractable pain (but not dying) for whom the burdens of continued treatment outweigh its benefits.³³ Kopelman maintains that the Baby Doe Rules would not permit this approach, and that they wrongly single out for infants under one year of age a set of rules that most adults would not tolerate for themselves.³⁴ She advances the Best Interests Standard as a fairer and more compassionate approach.

William J. Winslade, Professor of Philosophy of Medicine, Preventive Medicine and Community Health, and Psychiatry and Behavioral Sciences at the University of Texas Medical Branch, Galveston, explores the principle of vitalism in ethical decision-making for extremely premature infants.³⁵ He argues that, while it is not ethically obligatory, vitalism is ethically relevant and is a permissible ethical value for parents and health professionals to hold

32. *Id.* at 916.

33. *Id.*

34. *Id.* 923, 917.

35. William J. Winslade, *Personal Reflections on Extremely Premature Newborns: Vitalism, Treatment Decisions, and Ethical Permissibility*, 25 GA. ST. U. L. REV. 931 (2009).

in making treatment decisions for such infants. He also advocates that treatment decisions should be individualized and contextualized, and that balancing ethical values rather than applying legal rules provides a better basis for sound decision-making. He illustrates these propositions with three case studies in which he was personally involved yet tried to remain as objective as possible in the respective circumstances.

Winslade was a paid consultant during the litigation of the highly publicized Sidney Miller case in Texas.³⁶ Sidney's mother had come to the hospital in premature labor, and after consulting physicians about prospects for the infant, she and her husband asked that "no heroic measures" be provided at birth and to "let nature take its course."³⁷ Despite their request, the twenty-three week, 615-gram infant was resuscitated in the delivery room, and after extensive and on-going medical interventions she is still alive today, with significant physical and mental impairments. Winslade concludes that the parents' decision not to resuscitate at birth was both reasonable and responsible. On the other hand, he also believes that had they instead chosen aggressive treatment at birth based on vitalism, that decision also would have been ethically permissible, just as it would have been permissible after resuscitation to switch from aggressive to comfort care in light of the girl's subsequent catastrophic medical conditions.³⁸

In the second case, Winslade served as an ethics consultant to parents of an extremely premature infant born at twenty-five weeks and weighing less than 1,000 grams. The parents were reluctant to question the physicians, and according to Winslade, "they had been kept in the dark by peremptory reassurances that everything was stable."³⁹ A colleague asked if Winslade would help the parents navigate information-gathering and decision-making. Winslade

36. *Miller v. HCA, Inc.*, 118 S.W.3d 758 (2003). Professor Winslade ultimately did not testify at trial, and was not involved in the post-trial appeals.

37. *Id.* at 938.

38. *Id.* at 939.

39. *Id.* at 951.

sought a second opinion from a neonatologist whom he considered to be a “conservative, vitalist leaning physician” and who thought the infant’s prognosis was very poor or perhaps terminal.⁴⁰ Emphasizing the importance of fully and realistically informing parents about their infant’s prognosis, he argues that a vitalist decision by the parents to continue aggressive life support would have been ethically permissible, although their ultimate decision to choose pediatric hospice care was also ethical under the circumstances.

In the third case, Winslade was engaged by a company that provides utilization review for a large medical insurance group. He considers whether it was ethical for physicians to honor parents’ demands for complex aggressive life support for a twenty-six week, 760-gram infant who continuously remained on ventilator support for eight months until his parents agreed to limiting care a few days before he died. Winslade thought the treatment was “excessive,” and the benefits administration company questioned whether the costs of treatment (\$2.8 million) were justified. Employing the well-known four-quadrant model for ethical decision-making,⁴¹ Winslade again expresses concern about the adequacy of information provided to the parents. He nevertheless concludes that had they been fully and realistically informed about their child’s prognosis, it would have been ethically permissible, under a vitalist approach, for them to request full aggressive care, even if others would disagree with that decision.

PROCESS: HOW SHOULD DECISIONS INVOLVING SERIOUSLY ILL INFANTS BE MADE?

Acknowledging that the Baby Doe Rules have not been widely enforced as a practical matter, Thomas J. Balch, who is an attorney and the Director of the Robert Powell Center for Medical Ethics,

40. *Id.* at 950.

41. ALBERT R. JONSEN, MARK SIEGLER, & WILLIAM J. WINSLADE, *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* (McGraw-Hill 6th ed., 2006).

strongly challenges the current alternative practices in hospital settings. He focuses on the use of hospital ethics committees to make life-and-death treatment decisions for infants with disabilities under a Best Interests Standard, and concludes that the ethics committee process is not consistent with fundamental fairness.⁴²

Balch surveys the history of institutional ethics committees for resolving disputes involving life-and-death health care decisions. He argues that their original advisory function has evolved into a decision-making function for families and patients, and that these committees wield enormous power yet are largely insulated from liability for their decisions due to state immunity statutes. Because the lives of disabled infants are at stake, and because life is a constitutionally protected right,⁴³ Balch subjects the ethics committee process to a procedural due process analysis, and finds it lacking in basic procedural protections.

He argues that the Best Interests Standard typically applied by ethics committees in clinical settings is unconstitutionally vague, thus providing inadequate notice of the committee's reasons for its contemplated action. Analogizing the Best Interests Standard to statutory prohibitions against engaging in conduct that "annoys" a police officer or against "contemptuously" treating the U.S. flag, which have been ruled unconstitutionally vague, Balch argues that the Best Interests Standard likewise fails to advise surrogates for infants with disabilities what evidence they must marshal in order to prevent a denial of life-saving treatment for their infant.⁴⁴

Observing that due process requires neutrality or independence of the decision maker, Balch also challenges whether an ethics committee can be a neutral decision maker, for most committee

42. Thomas J. Balch, *Are There Checks and Balances on Terminating the Lives of Children with Disabilities? Should There Be?*, 25 GA. ST. U. L. REV. 959, 983 (2009).

43. Balch acknowledges that state action is required for application of 14th amendment due process protections, and that such state action is not present when ethics committees at private (rather than government) hospitals resolve cases involving infants with disabilities. He nevertheless adopts the due process paradigm for such cases because it embodies the tenets of fundamental fairness and thus serves as a template to evaluate the fairness and propriety of ethics committee procedures. *Id.* at 963.

44. *Id.* at 976.

members are affiliated with the hospital staff. Urging that due process requires that surrogates have a right to counsel at an ethics committee hearing where denial of life-saving treatment is contemplated, he argues for other procedural safeguards akin to those in administrative hearings in contested cases. Though he would doubtless prefer more widespread implementation of the Baby Doe Rules over the current alternative practices in most hospital settings, Balch acknowledges current clinical reality and subjects it to stringent due process analysis, concluding that it does not comport with fundamental fairness.

Robert D. Truog, Professor of Medical Ethics, Anaesthesiology, and Pediatrics at Harvard Medical School, begins his essay with the controversial Texas case of Sun Hudson, a baby who suffered from a lethal form of dwarfism and from whom doctors unilaterally withdrew life support over the objection of his mother but in accordance with the Texas Advance Directives Act.⁴⁵ Taking this case as his starting point, Truog provides a thoughtful reflection on the meaning of medical futility, when health care professionals consider continued aggressive treatment medically inappropriate (like Sun Hudson's case). He also carefully evaluates two procedural approaches that have been adopted to resolve disputes over futile care: the Texas statute and the hospital policy at Children's Hospital Boston.

Truog undertakes a "differential diagnosis" of the concept of futility, building on the concepts of power, trust, hope, money, and suffering. With respect to *power*, he observes that during the past few decades, the ethical questions have shifted from patients' rights to refuse treatment (now largely recognized) to patients' or surrogates' rights to demand treatment (over which there is little consensus). Skepticism or lack of *trust* among patients and families resisting physicians' attempts to deny treatment perceived to be possibly beneficial should not be surprising, says Truog, because most futility cases to date have involved disadvantaged groups who have been

45. Robert D. Truog, *Medical Futility*, 25 GA. ST. U. L. REV. 985 (2009).

previously denied access to health care in other contexts. *Hope* against all odds is just human nature (look at the success of lotteries), according to Truog, and has a place in the compassionate care of patients.

Truog observes that while *money* should in theory play no role in futility decisions (if a treatment is futile, it's not worth doing no matter how much or how little the cost), in fact futility concerns have been intertwined with issues of saving money and cutting costs. He argues that targeting vulnerable cases like Sun Hudson for tacit allocation of resources in the name futility while ignoring other expensive and useless drug treatments for paying patients is both unfair and ineffective. Evidence-based research suggests that eliminating all so-called futile care would produce relatively little cost-savings.⁴⁶ As for *suffering*, Truog believes more serious attention should be given to the suffering of everyone involved—patients, families, and caregivers.⁴⁷

Truog compares the Texas Advance Directives Act (TADA), which he regards as seriously flawed and stacking the deck in favor of physicians over patients so as to give physicians virtually absolute decision-making authority,⁴⁸ with the futility policy at Children's Hospital Boston, which he helped to develop a decade ago. He stresses that the process for resolving futility disputes is central to evaluating the legitimacy of their outcomes, and raises due process objections to the Texas statutory procedure, similar to those that Balch raises in the context of hospital ethics committees, including lack of neutrality in the decision makers who nonetheless wield significant power.⁴⁹ Truog also criticizes the lack of court oversight under TADA for the decisions of hospital ethics committees to unilaterally terminate treatment over family objection, with judicial review limited to extending the waiting period before termination. By contrast, says Truog, the policy at Children's Hospital Boston has

46. *Id.* at 993.

47. *Id.* at 996.

48. *Id.* at 988.

49. *Id.* at 999.

never been implemented unilaterally to terminate treatment, probably due to the greater options that the policy provides to families as well as to the intensive efforts undertaken to reach mutual resolution.⁵⁰

Thomas Wm. Mayo, who is the director of the Cary M. Maguire Center for Ethics and Public Responsibility and Associate Professor at SMU's Dedman School of Law, has first-hand experience with the Texas Advance Directive Act, as he has been a member of the advisory panel to the Texas legislature on this law since 1998. Mayo emphasizes that nothing in the TADA changes the impact of the Baby Doe rules on clinical practice in Texas. After the TADA's 2003 amendment to encompass medical decision-making for minors, the state's Child Protective Services officials still retain authority to intervene in any case where they believe that medically indicated treatment is being withheld from a disabled infant with a life-threatening condition.⁵¹

Mayo considers objections that have been raised against the TADA, including those raised by Truog. Like the concerns reflected in the essays by Balch and Truog, the principal criticism has been that there are insufficient procedural protections for patients and surrogates under the Act against biased, flawed, or inappropriate decisions by treating physicians.⁵² Defending the Act, Mayo discusses the advantages of utilizing the in-house ethics committee approach over resort to the courts, particularly with respect to professional expertise in medical decision-making.

Mayo also argues that the Act's critics have fundamentally misinterpreted the Act as precluding judicial review of the underlying merits of a case that could be brought under the TADA.⁵³ Acknowledging that there is nothing in the Act that explicitly provides for judicial review of the substantive treatment decision, Mayo observes that there was widespread agreement among the advisory panel's early discussions that such judicial review would be available under usual procedures for declaratory and injunctive relief. According to Mayo, spelling out these procedures in the TADA

50. *Id.*

51. Thomas W. Mayo, *The Baby Doe Rule and Texas's "Futility Law" in the NICU*, 25 GA. ST. U. L. REV. 1003, 1007 (2009).

52. *Id.*

53. *Id.* at 1010.

would have been unnecessarily redundant, and nothing in TADA precludes substantive judicial review of disputes over medical decision-making.⁵⁴

Mayo proposes several amendments to address critics' concerns and clarify the scope of the Act.⁵⁵ He recommends making the availability of substantive judicial review more explicit in the Act. He also suggests limiting civil immunity from liability to monetary damages, but allowing injunctive relief. In addition, he observes that disputes over the care of competent patients who have decision-making capacity should not come within the Act's scope. To address discrimination concerns raised by disability advocacy groups over the Act's applicability to patients with irreversible conditions, Mayo recommends limiting its scope to patients with terminal conditions. He also proposes extending the Act's time deadlines to allow the families of patients more opportunity to prepare for review or to find an alternative willing provider, and he suggests that there be additional opportunities to utilize informal dispute-resolution mechanisms before and during the review process.

Ellen Waldman, Professor of Law and Director of the Mediation Program at Thomas Jefferson School of Law, is concerned that there may be too much focus these days on "good process," reflecting unrealistic hopes that procedural tools such as mediation can resolve disputes over futility and the treatment of marginally viable lives.⁵⁶ Waldman takes as her starting point that, to date, there is no societal consensus on the meaning of futility in medical contexts, and that because the only emerging consensus is that no consensus is possible over substantive standards for defining when care is futile, the focus has shifted to the process for resolving futility disputes. Waldman observes that mediation's procedural power normally occurs against a backdrop of legal and ethical norms. However, because there are no substantive norms that clearly delineate the respective rights of the parties disputing over whether aggressive care is legally or ethically

54. *Id.* at 1010–13.

55. *Id.* at 1013.

56. Ellen Waldman, *The Baby Doe Regulations and Tragic Choices at the Bedside: Accepting the Limits of Good Process*, 25 GA. ST. U. L. REV. 1019 (2009).

required in extreme (arguably futile) cases, Waldman contends that reliance on process to resolve these disputes is likely to fail in many cases.⁵⁷

Waldman provides a clear roadmap for understanding why mediation does not work as well in these cases as it can in other settings. To begin with, futile care disputes often reflect radically different values among families and caregivers over whether marginally viable life is worth preserving, let alone whether it is worth the costs of preserving it. Attempting to negotiate over such core human, religious, personal, or professional values is not likely to produce much constructive or conciliatory movement on either side.⁵⁸

Mediation is a process of managing information, emotion, and expectations, according to Waldman. Mediation can be useful when the source of the conflict is lack of information or lack of good communication, which can result in misunderstandings. In this circumstance, a mediator can helpfully broaden the parties' information base and understanding of each side's needs and perspectives and thus help the parties resolve their conflict. In cases involving futility disputes, however, families may simply reject the medical information provided, or even if they accept it, disagree over its implications for treatment.⁵⁹ In addition, the intense and complex set of emotions among families whose loved one's very existence is at stake can significantly compromise the chances of rational resolution.

Waldman argues, moreover, that contemporary reliance on "good process" is likely to empower families (who have nothing to lose by continuing a procedural contest) and to prompt providers (who are averse both to risks and to litigation) to capitulate to family demands for continued aggressive care. Acknowledging that emboldening families and cowing clinicians⁶⁰ may be the substantive outcome that society wants, Waldman nonetheless challenges us to consider,

57. *Id.* at 1023–24.

58. *Id.* at 1034.

59. *Id.* at 1031–32.

60. *Id.* at 1038.

openly and transparently, whether this is so, rather than try to mask this substantive outcome behind a veneer of “good process.” Thus, our current focus on process leads us inexorably back to substance, and Waldman encourages renewed societal efforts toward crafting an acceptable definition of futility and acceptable limits of medical treatment. The process we should be focused on, says Waldman, is on gaining societal consensus on the norms or standards for making difficult decisions over when enough treatment is enough.⁶¹

THE INFLUENCE OF DISABILITY LAW AND POLICY ON THE BABY DOE RULES

Mary Crossley, Dean and Professor of Law at the University of Pittsburgh School of Law, reflects on how disability law and policy may be implicated in medical treatment decisions for newborns.⁶² She makes a crucial distinction between, on one hand, a newborn like the original Indiana Baby Doe, who had a mental disability (Down syndrome) and an independent medical condition requiring life-saving treatment, and on the other hand, the extremely premature newborn whose medical needs are more complex and whose prognosis (probability of survival with treatment and extent of future disabilities if the child survives) are much more uncertain than Baby Doe’s was. In the former case, the treatment was known to be effective in ameliorating Baby Doe’s life-threatening condition, and if provided the child would have survived with a known disability. In the latter case, however, there is often great prognostic uncertainty about the extremely premature newborn’s chances of survival and the future nature or extent of disability. Crossley’s essay poses challenging questions about how the increased complexity in the latter cases might change the nature of parental decision-making for these infants as well as how disability concerns are implicated in these decisions.⁶³

61. *Id.* 1039–42.

62. Mary Crossley, *Rescuing Baby Doe*, 25 GA. ST. U. L. REV. 1043 (2009).

63. *Id.* at 1046.

Because the parents and physicians involved in the original Baby Doe case likely would have consented to treatment had the infant not had Down syndrome, Crossley suggests that to the extent that the refusal of treatment in that case was influenced by societal and medical biases about people with disabilities, it seems to reflect a kind of discrimination that our society finds objectionable. Decision-making for extremely premature newborns, however, for whom everything about their future is uncertain, seems likely to be influenced more by the expectation of, rather than the existence of, a disability. She also suggests that insistence on aggressive treatment to provide any chance, however remote, that a marginally viable newborn might survive may reflect a perspective concerned more with vitalism than with disability rights.⁶⁴

Crossley examines the Baby Doe Rules in their present context—as a species of child welfare law rather than discrimination law—and considers how such law governs parental decision-making about medical treatment for children. As applied to the special parent-child relationship, tort law’s “duty to rescue” requires parents to undertake reasonable steps to rescue their children from harm, but does not require them to place themselves or their other children in peril to save a child. Because of strong constitutional protections for parental autonomy and the rights of parents to make a range of decisions affecting the welfare of their children, courts have overridden parental decisions only when necessary to protect their child from significant harm, and have not required medical treatment for all potentially life-threatening conditions in older children, particularly when the proposed treatment’s benefits are not clear.⁶⁵ Crossley acknowledges that the Baby Doe Rules’ narrow exceptions for non-treatment serve the laudable goal of limiting death-dealing decisions based on bias against disabled lives, but she suggests that the Rules are nonetheless in tension with other socially valuable goals like protecting parental autonomy in uncertain and complex cases.⁶⁶ She

64. *Id.* at 1048.

65. *Id.* 1053–54.

66. *Id.* at 1055.

advances the case for support from disability advocates for the fully educated and informed, yet limited, exercise of parental discretion in these difficult cases involving marginally viable newborns.

Anita Silvers and Leslie Pickering Francis, Professors of Philosophy and Chairs of the Philosophy Departments at San Francisco State University and the University of Utah, respectively, draw a similar distinction between the kinds of newborns that prompted the first set of Baby Doe Rules (like Baby Doe with Down syndrome, who was denied surgery that in all likelihood would have been provided to a baby who did not have a similar mental disability) and the kinds of newborns that present some of the most difficult treatment questions today (infants born extremely prematurely or at very low birthweights whose prognosis for survival is uncertain, and whose diagnosed medical conditions may or may not lead to disabilities).⁶⁷ Under the current Baby Doe Rules, they argue, the regulatory scheme provides special treatment for disabled infants that older disabled children or children without disabilities may not be provided, rather than providing disabled infants protection against discriminatory denial of equal services that non-disabled infants would be given, which anti-discrimination rationale was the focus of the first set of the Baby Doe Rules.⁶⁸

Silvers and Francis carefully trace the history of the two sets of Baby Doe Rules. The initial federal policy response to denials of life-saving treatment for newborns with congenital anomalies resulting in mental disability was to invoke Section 504 of the federal Rehabilitation Act of 1973. The Secretary of Health and Human Services promulgated the first set of Baby Doe regulations under this Act, interpreting the Act to allow federal intervention to prohibit hospitals from withholding medically indicated treatment from a handicapped child solely on the basis of handicap. These regulations

67. Anita Silvers and Leslie Pickering Francis, *Playing God with Baby Doe: Quality of Life and Unpredictable Standards at Start of Life*, 25 GA. ST. U. L. REV. 1061, 1072 (2009). Professor Silvers spoke at the symposium. Professor Francis is also a Professor of Law.

68. *Id.* at 1180 (“Rather than authorizing claims *against* inequality of medical treatment based on disability, and specifically against the withholding of necessary treatment based on disability, CAPTA assigns an entitlement to medical treatment based on disability.”).

were ultimately overturned by the Supreme Court for several reasons, among them that there had been no showing that hospitals were in fact withholding treatment from disabled infants on the basis of disability; rather, they had not treated the infants because they lacked parental consent to do so, and parents are not subject to the federal Act.⁶⁹

The authors discuss the shift in focus from disability discrimination in the first set of Baby Doe Rules to child abuse and neglect in the second and current set of rules, which were promulgated by Congress as amendments to the Child Abuse Prevention and Treatment Act.⁷⁰ They argue that the original anti-discrimination impetus to protect disabled newborns from discrimination was replaced with another, categorical directive to save newborn lives, however low were the chances that aggressive treatment might save them: “language of CAPTA has shifted attention from the comparative right to equality of meaningful access to medical treatment to the categorical right to life.”⁷¹ The current rules thus suggest more aggressive grounds for federal intervention than was the case under the Section 504 regulations, and they could require life-saving treatment for a disabled infant despite a small likelihood of effectiveness, which might not be required for a non-disabled infant for whom medical decision-making is judged under a different standard.⁷²

Silvers and Francis urge that the Baby Doe Rules be revisited in light of the original focus of regulation in this area—the prevention of disability discrimination—because disability biases still operate in our society, which may be obscured by prognostic uncertainty for extremely premature infants, and which may be masked by vague yet alarming predictions and exaggerated claims about the potential burdens posed by disabled children. These authors conclude that the

69. *Bowen v. Am. Hosp. Assoc.*, 476 U.S. 610 (1986).

70. Child Abuse Amendments of 1984, Pub.L. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101-5106i (2006) and implemented in relevant part by 45 C.F.R. § 1340.15 (2008)).

71. See Silvers & Francis, *supra* note 67 at 1093.

72. *Id.* at 1079.

Rules should be clarified to demonstrate an entitlement of disabled infants, not to a right to life nor to special treatment, but rather to procedural equality in deciding what treatment they should be provided.⁷³ They encourage the development of procedural guidelines that incorporate the “ethics of incertitude” in medical prognosis, and that would help in avoiding disability discrimination when dealing with uncertainty about an infant’s prospects for disability.⁷⁴

CONCLUSION

As symposium preparations were underway in the Fall of 2008, *The New York Times* reported global statistics that ranked the United States as 29th in the world for infant mortality as of 2004 (tied with Poland and Slovakia), down from 12th in the world in 1960.⁷⁵ Two-thirds of the annual 28,000 infant deaths in the United States are in pre-term babies, and the rate of premature births is increasing. Clearly, the serious challenges in providing appropriate health care to sick and premature newborns have not diminished since the Baby Doe Rules were enacted twenty-five years ago.

And yet as a society we have not reached consensus over what substantive standards we should use to make treatment decisions for highly at-risk infants. The opening symposium speaker, Mark Mercurio, observes that “the line has moved, but the fundamental issue is the same,” and that whether aggressive treatment should be optional or even offered in some cases depends upon the extent of an infant’s potential neurological disabilities and concerns about his quality-of-life, and that physicians, ethicists, and lawyers continue to disagree over the relevance of these and other concerns.⁷⁶

The Baby Doe Rules offer one set of standards for making these treatment decisions, which many interpret as reflecting a “do

73. *Id.* at 1063–1064.

74. *Id.* at 1094.

75. Gardiner Harris, “Infant Deaths Drop in U.S., but Rate Is Still High,” *The New York Times* (Oct. 16, 2008).

76. Mercurio, *supra* note 14, at 855.

everything” approach if there is any chance of saving an infant’s life in the present, without reference to possible quality-of-life concerns in the future. Are these the right standards? Responses vary, and the Rules continue to spark criticism. Bhatia argues that quality-of-life should play a role in the care of newborns, particularly with respect to palliative care. Kopelman forthrightly argues that the Rules set the wrong standards, and that treatment decisions for newborns should be made under the same standards used for older children and incapacitated adults—namely, the Best Interests Standard, which allows individualized decision-making in light of the net benefits and burdens that treatment poses for an infant. Winslade suggests that the vitalism principle reflected in the Rules is a permissible, but not obligatory, ethical basis for continuing aggressive treatment despite disagreements among health care providers. Silvers and Francis argue that guarding against disability biases should be a substantive factor in decision-making, but acknowledge that anti-discrimination principles are not the focus of the current Baby Doe Rules. Crossely offers that principles of child welfare law should inform decision-making in the care of very sick infants. And Sayeed argues that whatever the right standards or factors in decision-making may be, physicians should be more transparent about how they are applying them in actual clinical practice.

With so many diverse and well-reasoned views on the normative standards for decision-making in the newborn nursery, it is little wonder that there has been a shift in the contours of the debate from the substantive norms to the processes by which these decisions are handled. Balch criticizes current practices among hospital ethics committees, which he argues fail to provide adequate due process protections and fundamental fairness in deliberations over infant treatment. Truog levels similar criticisms at the statutory process enacted in Texas that allows unilateral termination of treatment over a surrogate’s objection, but he also believes that hospital futility policies can provide a good basis for collaborative and consensus-oriented decision-making. Waldman cautions that even if the processes for decision-making are legally and ethically appropriate,

many of these highly-charged decisions about infants at the edge of meaningful existence will simply not be amenable to collaborative resolution in practice, no matter how good the process may be in theory.

Thus, after twenty-five years, the Baby Doe Rules have not resolved how decisions about appropriate treatment for seriously ill and extremely premature infants should be made, nor have they forged a societal consensus over the standards for decision-making. While the Rules may not be openly used to guide decision-making in much of clinical practice today, they continue to reflect the underlying ethical and societal tensions that prompted their enactment in the first place and that still need to be resolved.

APPENDIX A

BABY DOE RULES

Child Abuse Amendments of 1984 (PL 98-457), updated at 42 U.S.C. § 5106

Child Abuse Prevention and Treatment Act (CAPTA)

Overview: 42 U.S.C. § 5106a (2006) authorizes the Secretary of the U.S. Department of Health & Human Services to make grants to states to improve their child protective services systems. To be eligible for such a grant, a state must provide a number of assurances, including the guarantee that it will address medical neglect. Specifically, pursuant to 42 U.S.C. § 5106a(b)(2)(B) (2006), the state shall provide:

(B) an assurance that the State has in place procedures for responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for--

- (i)** coordination and consultation with individuals designated by and within appropriate health-care facilities;
- (ii)** prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions); and
- (iii)** authority, under State law, for the State child protective services system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to

prevent the withholding of medically indicated treatment from disabled infants with life threatening conditions . . .

Definition: 42 U.S.C. § 5106g(6) (2006) provides:

(6) the term “withholding of medically indicated treatment” means the failure to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician’s or physicians’ reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician’s or physicians’ reasonable medical judgment --

(A) the infant is chronically and irreversibly comatose;

(B) the provision of such treatment would--

(i) merely prolong dying;

(ii) not be effective in ameliorating or correcting all of the infant’s life-threatening conditions; or

(iii) otherwise be futile in terms of the survival of the infant; or

(C) 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.

APPENDIX B

THE HYPOTHETICAL SCENARIO OF SOPHIE: EXTREME PREMATUREITY

Initial facts: Ms. Anna Ariel is a pregnant 37-year-old woman who has had good prenatal care. She is in premature labor at 23 and 1/7 weeks gestation by 1st trimester ultrasound examination. She is carrying a singleton female fetus. She and her husband are well educated, have demanding professional jobs, and have purposely delayed becoming parents for the sake of their careers. They now strongly desire this pregnancy and are prepared to “do whatever it takes” to try and preserve the life of the fetus. Thus, they ask that whatever active measures that might improve the odds of long-term survival be taken immediately.

1st question: *Is there an obligation to provide antenatal steroids, which might accelerate fetal lung maturity and might increase the chances of neonatal survival? Is there an obligation to provide a c-section delivery if requested, if the fetus appears malpositioned for vaginal delivery or if the fetus demonstrates an intolerance to labor?*

Case progression: Attempts at tocolysis (forestalling labor progression through medical management with medications and bedrest) fail after 24 hours. Steroids have been given once. A c-section is performed and a female neonate is born weighing 475 grams (full-term birthweight is typically 3 kilograms). After the umbilical cord is separated, the infant cries faintly, and her pulse is around 100 beats per minute as she rests under warm lights (typical newborn pulse rate is over 120 beats per minute). The parents name the baby Sophie.

2nd question: *Assuming the parents desire “everything to be done”, is there an obligation to provide a full resuscitation? If yes, is the obligation based on the law? If so, which one(s)?*

Case Progression: Sophie is intubated (placed on a ventilator to help her breathe) and stabilized and brought to the neonatal intensive care unit (NICU) for further care. Her first 24 hours are fairly stable, and she is on modest mechanical ventilator settings and minimal blood pressure medication for cardiac support. The next day, Sophie is clinically less responsive and has a fall in hematocrit (red blood cell count), which may be indirect evidence of internal bleeding. The attending physician obtains a head ultrasound around 48 hours after birth, and notices an extensive hemorrhage involving one ventricle and one side of the brain matter (comparable to grade 4 IVH). This is generally thought to be a serious bleed into the brain which can result in significant maldevelopment of the brain as the baby grows. When extensive, this kind of brain injury early in life correlates with later physical and mental handicap in older children. Sophie has not required any increase in support but needs a blood transfusion to improve oxygen-carrying capacity. The doctor discusses the findings with the parents and the prognostic implications if Sophie survives to discharge, and recommends withdrawing support, citing the best interests of the newborn. The parents are upset and sad, but need time to process. A little after 96 hours after birth, they agree. In the doctor's experience, babies like this one who have been cared for in this NICU, now have a better than 50% chance of survival to discharge if intensive care is maximally provided going forward.

3rd question: *Does the collective decision by parents and providers violate state laws that reflect the federal Baby Doe standards established by the CAPTA amendments in 1984? If so, does anyone in the hospital have an obligation to contact the local child protective services agency?*

Alternate case progression: Same facts as just before, but the parents request the physician to continue to provide maximal support. The physician complies, and Sophie is eventually extubated to CPAP (which is a less invasive mode of respiratory support that supplies distending air pressure to the upper and lower airway through prongs

that sit in the baby's nose) and at 6 weeks of life is advancing slowly on about half-volume milk feeds through a temporary feeding tube. Her neurological injury is fairly stable. There is a small area of cyst formation in the brain matter where the initial injury occurred, but she has not developed post-hemorrhagic hydrocephalus, which involves dilation of fluid spaces inside the brain that can lead to compression of the grey and white matter and maldevelopment of a growing brain. Sophie has not yet had her first eye exam. Her eyes are at risk of an eye disease called retinopathy of prematurity, which can lead to blindness but in most cases leads to a need for corrective prescription lenses. (Babies need several eye exams in the first few months of life to follow the development of the retinas.)

The next day, Sophie develops bloody stool, distends her abdomen, and the clinical picture is consistent with necrotizing enterocolitis (NEC), which is an inflammatory process of the intestines thought to be due to a combination of reduced blood flow to the gut and bacterial overgrowth/infection in an injured area of bowel. The physician discusses the implications of this with the parents, noting that mortality with this condition at this hospital is around 20% even after surgical intervention. Sophie appears to need re-intubation at this time due to the severity of her illness.

4th question: *May the doctor revisit withdrawal of care with the family and offer comfort care? Are there any legal obstacles?*

Case progression: The parents desire to proceed with all available cares. Sophie manages to survive the episode of NEC and has 15 cm of small bowel resected, which is enough to potentially affect the complete absorption of nutrients after feeding, but many babies with this amount of bowel left are eventually able to adapt and are able to grow exclusively on full milk/formula feeds. She is now 4 months old, but unfortunately has been unable to wean from the ventilator since the NEC episode. It now appears she has upper airway compromise from prolonged intubation on top of severe chronic lung disease. In the doctor's experience, most babies who have this degree

of compromise eventually need a tracheostomy (a surgically placed hole in the neck which allows for air to enter the lungs bypassing the mouth and upper airway) to successfully transition to a rehabilitation facility. Sophie is no longer acutely sick, but has multiple chronic medical problems including, poor nutrition, retinopathy of prematurity, periventricular cystic leukomalacia (which means she is likely to have some degree of physical handicap as she develops her motor functions), and chronic lung disease. Her parents are now feeling the weight of the world on their shoulders after 4 months in the NICU and believe it would be in their daughter's best interests to not have a tracheostomy. They request that the physician extubate her to CPAP and make her as comfortable as possible. They specifically do not want her reintubated. In this hospital's experience, if a tracheostomy is provided, Sophie has a greater than 90% chance of eventually being able to be discharged to a rehabilitation facility. Her long-term outcome is worrisome, but she may eventually be able to walk with assistance, breathe without the need for a ventilator or oxygen, receive a special education into high school, and have her vision somewhat corrected with surgery/prescription eyeglasses. In other words, the physician now believes she is likely to survive with significant impairments if she is given a tracheostomy.

5th question: *May the physician legally redirect to comfort care alone now?*

