Process - the Best Medicine for Seriously Ill Infants

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Imagine a couple is anxiously awaiting the birth of their first child. Their hearts are filled with joy. Their heads are filled with visions of sharing so many special events that make up the fabric of American life. Suddenly, they face impending tragedy. Contractions begin. This expectant mother, almost four months prior to her due date, is rushed to the hospital.1 An ultrasound reveals this mother’s fetus weighs about 629 grams or 1 1/4 pounds and has a gestational age of approximately twenty-three weeks.2 A full-term pregnancy is forty weeks. Because of the fetus’s prematurity, the physicians begin to administer a drug designed to stop labor.3 Subsequently, the physicians discover that the mother has an infection that could endanger her life and they must induce delivery to save the mother.4 The physicians inform the parents-to-be that if they induce delivery, the infant will have little chance of being born alive.5 The physicians also inform the parents-to-be that if the infant is born alive, it will most probably suffer severe impairments, including cerebral palsy, brain hemorrhaging, blindness, lung disease, pulmonary infections, and mental retardation.6 Very difficult decisions must be made in the minutes, hours, and weeks that lie ahead. The parents, physicians, in-house counsel of the hospital, an institutional ethics committee, a guardian ad litem, potentially a state prosecutor, and a judge may face many difficult decisions regarding the life of this child.

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2 Id.
3 Id.
4 Id.
5 Id.
Introduction: What limitations are imposed on the right to refuse medical treatment on behalf of an infant with a life-threatening condition?

The birth of a child with either a life-threatening disease or a congenital defect who requires life-sustaining treatment poses a myriad of medical, legal, ethical, religious, and social concerns. This paper examines the complex hierarchy of federal and state constitutional law, statutory law and common law doctrine as applied to seriously ill infants. It analyzes the relative rights and interests of the infant, her parents, the state, and the medical community as they relate to a host of recurring medical treatment decisions. The unique perspective of health law which recognizes a triangular relationship among law, medicine, and society serves as the contextual framework for this discussion. In examining how this body of law has developed, we come to understand how the scope of procedural safeguards afforded, both formal and informal, promote the protection of all interested parties.

In Part I, the framework of constitutional rights and interests of the respective parties set the stage for analyzing the parents' right to refuse treatment on behalf of their seriously ill infant. Four constitutional principles underpin every decision. First, in the case of fetal-maternal conflict, the fetus has no cognizable constitutional interests to balance against the mother's liberty interest. In practice, the right to terminate a pregnancy or refuse medical treatment to benefit the fetus is protected under the medical principle of patient autonomy. Second, the fundamental right to family autonomy, which includes making health care decisions for one's child, is deeply rooted in our historic tradition. This right creates a legal presumption that fit parents act in the best interest of their child when making difficult medical decisions. The right, however, is not absolute. Rather, the state's rights may be afforded constitutional protection when a compelling state interest exists. For the state to exercise its parens patriae power, in opposition to the parents wishes, the state necessarily must establish a threshold finding of some likelihood of medical neglect. Third, under the U.S. Constitution, the countervailing state interests are primarily protected through employing additional procedural safeguards and a heightened standard of proof. Fourth, in regards to procedural due process under the Fourteenth Amendment to the United States Constitution, the relevant inquiry is, "How much process is due?" If Comm'r, Dep't of Human Res. of Georgia v. J.R. is controlling, then “some kind of inquiry by a neutral factfinder” may satisfy due process requirements without holding a formal or informal judicial hearing.

7 Comm'r, Dep't of Human Res. of Georgia v. J.R., 442 U.S. 584 (1979).
8 Id. at 606.
In Part II, the rights and interests as expounded upon by the U.S. Legislature add shape to the competing roles of various parties. The primary debate centers upon interpreting the Legislature’s intent regarding the degree of deference to be accorded to physicians under federal law. Deference to medical judgment is alive and well under the Child Abuse Amendments, but is deference dead under the federal Emergency Medical Treatment and Labor Act?\footnote{Emergency Medical Treatment and Labor Act, 42 U.S.C. § 1395dd (2005) [hereinafter EMTALA].} Deference to medical judgment, as intended by Congress, is emblematic of the respect accorded to the private nature of the physician-patient relationship. Deference operates to limit unwarranted governmental intrusion into its citizen’s private medical affairs.

In Part III, the rights and interests affirmed in state constitutions, and their effect upon our jurisprudence is briefly summarized. Most states have held, at a bare minimum, that the rights and protections afforded under the United States Constitution are similarly held as fundamental rights under their respective state constitutions.

In Part IV, the relative rights and interests protected under state statutory law are examined through the jurisprudence involving informed consent statutes. From a chain of cases, the following informed consent doctrine is emerging in regards to seriously ill infants. Parents who wish to withdraw or withhold life-sustaining medical treatment against medical advice will not be accorded a post hoc remedy under informed consent doctrine where exigent circumstances create an exception, where there exists no viable treatment alternative and death will result without treatment, and where an accurate prognosis is unknowable even if treatment is administered.

In Part V, the relative rights and interests protected under the common law through substituted judgment doctrine and best interest doctrine are thoroughly examined. Some courts are making a distinction in the application of these doctrines based upon the relationship of the surrogate decision-maker to the infant. The distinction recognized is as follows. First, where the parents are in agreement with the physician’s medical judgment regarding withholding or withdrawing medical treatment from an infant, a reviewing court appropriately employs the doctrine of substituted judgment. Second, where the parents disagree with the physician’s medical judgment regarding withholding or withdrawing medical treatment from an infant, a reviewing court appropriately employs best interest doctrine. Similarly, where the infant is a ward or in the custody of the state, regardless of whether the infant’s advocate agrees or disagrees with the physician’s medical judgment, a reviewing court appropriately
employs best interest doctrine.

In Part VI, two additional concerns regarding the development of our jurisprudence are addressed. First, application of a heightened evidentiary standard, such as clear and convincing proof, may be justified when guarding against the risk of erroneous deprivation of a patient who was once competent, and now rendered incompetent, but unjustified in cases where the patient was never competent. Second, judicial intervention is generally unjustified absent a difference of opinion between the treating physician and the parents. Where a third party seeks judicial intervention, a threshold finding of medical neglect necessarily precedes a court order requiring a course of treatment when the parents and physician are in agreement about withholding or withdrawing treatment. The conclusion revisits the courts’ movement on two key doctrinal issues affecting family autonomy and health care policy.

Part I: Rights and Interests Protected under the U.S. Constitution:

A: In the case of fetal-maternal conflict, the fetus has no cognizable constitutional interests to balance against the mother’s liberty interest. In practice, the right to terminate a pregnancy or refuse medical treatment to benefit the mother is protected under the medical principle of patient autonomy.

Prior to her birth, a fetus is afforded no Constitutional protections. The Supreme Court of the United States has held that a woman has a constitutionally secured right to terminate a pregnancy.\(^\text{10}\) Given the existence of the right to choose recognized in *Roe v. Wade* and *Planned Parenthood of Southeastern Pennsylvania v. Casey*, the common law has allowed the development of a physician’s duty to exercise care in providing information that bears on that choice.\(^\text{11}\) A physician has an affirmative duty of “due care” to test, detect, diagnose, and disclose birth defects in a timely manner, and inform the mother of the possible effects on the child’s health.\(^\text{12}\) Scientific advances in prenatal health care provide the basis upon which parents may make an informed decision that *Roe* protects.\(^\text{13}\)

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\(^{11}\) Smith v. Cote, 513 A.2d 341 (N.H. 1986) (wrongful birth cause of action for negligent detection and failure to provide informed consent to pregnant mother exposed to rubella; subsequently, child born with congenital rubella syndrome).

\(^{12}\) *Id.* at 346-47.

\(^{13}\) *Id.* at 345-46.
“Under Roe, prospective parents may have constitutionally cognizable reasons for avoiding the emotional and pecuniary burdens that may attend the birth of a child suffering from birth defects.” Informed consent doctrine, with its origins rooted in the common law tort of battery, echoes the principle of one’s right to be free of bodily invasion consistent with the fundamental notion laid down in Roe and Casey. While a state may assert its interest in the protection of human life, through regulating the right to abortion even before fetal viability, the state may not impose an “undue burden” on the woman’s right to choose. Furthermore, “subsequent to viability, the State in promoting its interest in the potentiality of human life, may, if it chooses, regulate, and even proscribed, abortion except where it is necessary, in appropriate medical judgment, for the preservation of the life or health of the mother.” Stenberg v. Carhart preserves the right to undergo the controversial D & X procedure, commonly called the “partial birth abortion,” at a minimum as a health exception for the mother. Therefore, the mother, upon considering the potential birth defects of her unborn child, may exercise her right not to have this particular child.

Even in cases where the mother has not exercised her right to abortion, and evidence supports her intent to have the child, courts generally will not balance the interests of the fetus (or the interests of the state in protecting the fetus) against the interests of the mother. In re A.C. serves as one of the most compelling cases to illustrate the nature of the relationship and relative rights of a mother to her fetus. Even in this extreme case, where an otherwise healthy twenty-six and one-half week old fetus may suffer irreversible harm or death related to the terminally ill status of the mother, the mother will not be forced to undergo any treatment against her will to benefit her unborn child. Generally, a court will not “compel one person to permit a significant intrusion upon [ ] her bodily integrity for the benefit of another person’s health.”

Some have suggested that fetal cases are different, because a woman who has chosen to lend her body to bring a child into the world has an enhanced duty to assure

14 Id. at 347.
17 Id. at 921.
18 Id. at 915.
20 Id.
21 Id. at 1243-44; see also McFall v. Shimp, 10 Pa. D. & C.3d 90 (1978) (court refused to order Shimp to donate bone marrow which was necessary to save the life of his cousin).
of the welfare of the fetus, sufficient even to require her to undergo caesarean surgery (C-section). The In re A.C. court, however, concluded that a fetus cannot have rights in this respect superior to those of a person who has already been born.

A.C. hoped to battle her terminal cancer for two additional weeks because her baby at twenty-eight weeks gestation would have a much improved chance of survival. Due to sudden medical decline, however, A.C. was only expected to live another twenty-four to forty-eight hours. Fading in and out of consciousness, her physician testified that she consented to the caesarean procedure. Later that day, the court convened at her bedside to confirm her consent. Although her voice was left inaudible from the tube in her windpipe, in this dying mother's "very clearly mouthed words" she stated "I don't want it done, I don't want it done" in response to her physician's attempt to gain informed consent to perform a caesarean section. Curiously enough, in one of the most heart-wrenching decisions of the District of Columbia Court of Appeals, the Court found this terminally ill pregnant mother incompetent.

Competence presupposes the capacity to make informed decisions. The finding of incompetence, therefore, invalidated the mother's refusal to give informed consent to the C-section. Once found incompetent, this Court held that the doctrine of substituted judgment applied and it was determined that the mother would have wanted the procedure performed to save the life of her child. In effect, this Court preserved her right to be free of unwanted bodily invasion through finding that A.C. would have consented to saving her child if she was competent. Departing from the liberty interest "protected" in cases like In re A.C., a minority of courts have made a frontal attack on the rights of a mother-to-be, employing instead a balancing test when asked to order a pregnant woman to undergo medical treatment for the benefit of her fetus.

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24 Id.
25 Id. at 1250.
26 See id. at 1238-40.
27 Id. at 1240-41.
28 Id. at 1241.
29 Id.
30 See id. at 1247.
31 See id. at 1243.
32 Id. at 1247.
33 Id. at 1247.
34 See Raleigh-Fitkin-Paul Morgan Mem'l Hosp. v. Anderson, 201 A.2d 537 (N.J. 1964) (court ordered blood transfusions to save an unborn child over the objections of the Jehovah's Witness
In summary, the fetus is generally afforded no constitutional protections prior to her birth regardless of the mother's decision to bear the child. In contrast, every person has the right to refuse unwanted medical treatment.35 A competent person, a person who was once competent but is now incompetent, and a person who was never competent all have the right to refuse unwanted medical treatment if his or her wishes can be ascertained and satisfy the evidentiary standard of proof required by the state.36 The determination of competence versus incompetence, however, allows for manipulation of the outcome in difficult cases, as exemplified in In re A.C., which may defeat, rather than preserve, autonomy.

Autonomy is constrained by a threshold finding of competence.37 In evaluating competence, three common themes emerge.38 First, coherence; that is, whether the patient demonstrates an ongoing belief or value system that is objectively reasonable based upon the degree of invasiveness of treatment in relation to the probable outcome.39 Second, sincerity; that is, whether the patient solemnly pronounced his wishes consistently over time as opposed to a casual remark or emotional reaction made in response to witnessing a loved one die.40 Third, clarity; that is, whether the patient demonstrates a well thought out, consistent decision to refuse a specific type of treatment under specific circumstances.41
Competence is a legal status; however, the determination of competence is an exercise of medical judgment. Competence is not a rigid or exacting standard, but rather competence is assessed in light of the nature of the decision to be made. For example, deciding whether to have turkey or a cheeseburger for lunch demands little in the way of competence, whereas deciding whether to undergo or forego a medical procedure with life or death consequences demands a great deal in the way of competence. Absent a finding of competence, courts frequently employ the doctrine of substituted judgment as a means to fulfill the principle of autonomy. In so doing, the In re A.C. Court found that A.C., if competent, would have wanted her child to live and subsequently ordered the procedure.

B: The fundamental right to family autonomy, which includes making health care decisions for one's child, is deeply rooted in our historic tradition. This right creates a legal presumption that fit parents act in the best interest of their child when making difficult medical decisions. The right, however, is not absolute. Rather, the state's rights may be afforded constitutional protection when a compelling state interest exists. For the state to exercise its parens patriae power, in opposition to the parents' wishes, the state necessarily must establish a threshold finding of some likelihood of medical neglect.

The Supreme Court has frequently emphasized the importance of family and shaped the contours of the rights accorded to the family unit through the principle of autonomy:

The rights to conceive and to raise one's children have been deemed "essential," Meyer v. Nebraska (1923), "basic civil rights of man," Skinner v. Oklahoma (1942), and "(r)ights far more precious... than property rights," May v. Anderson (1953). "It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for

42 Wright, supra note 35, at 36; see Loren H. Roth et al., Tests of Competency to Consent to Treatment, 134 Am. J. Psychiatry 279 (1977); see also President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Decisionmaking Capacity & Voluntariness, in 1 MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 55, 57-60 (1982).
43 Wright, supra note 35, at 36.
44 See infra Part V A.
obligations the state can neither supply nor hinder.” Prince v. Massachusetts (1944). The integrity of the family unit has found protection in the Due Process Clause of the Fourteenth Amendment, the Equal Protection Clause of the Fourteenth Amendment, and the Ninth Amendment.66

The earliest Supreme Court cases recognizing family autonomy involved the right of parents to control the upbringing of their children.47 Notably, these cases were decided during the Lochner era and expressly use substantive due process to protect parent’s rights.49 Although economic substantive due process was abandoned in 1937, the Supreme Court’s decisions of that era protecting parental decision-making are very much still followed.50

Historically, our jurisprudence has long adhered to the notion that parents generally “have the right, coupled with the high duty, to recognize and prepare [their children] for additional obligations.”51 “Surely, this includes a ‘high duty’ to recognize the symptoms of illness and to seek and follow medical advice.”52 The law’s concept of the family rests on a presumption that parents possess what a child lacks in capacity for judgment required to make life’s difficult decisions.53 Moreover, historically the law has recognized that natural bonds of affection lead parents to act in the best interest of their child thereby creating this legal presumption.54 This presumption, refined over time, holds that “fit parents” act in the best interest of their child.55 So long as a parent adequately cares for his or her children (i.e. is fit), there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent’s children.56

49 Id.
50 Id.
52 Parham, 442 U.S. at 602.
53 Wright, supra note 35, at 36-37; see Parham, 442 U.S. at 602.
54 Wright, supra note 35, at 37; see Parham, 442 U.S. at 602.
56 Wright, supra note 35, at 37; see Troxel, 530 U.S. at 68-69 (2000) (emphasis added).
As is generally the case with legal presumptions, experience and reality may rebut what the law accepts as a starting point.57 A state, therefore, is not without constitutional control over parental discretion in dealing with children when their physical or mental health is jeopardized.58 Upon a determination of abuse or medical neglect, the state may exercise its \textit{peregris patriae} power through the state’s department of social services and act on behalf of the child’s best interest.59

In summary, parental autonomy, in regards to making health care decisions on behalf of their minor child, is generally upheld absent a preliminary finding that their decision constitutes medical neglect.60 In such a case where the parent’s judgment is deemed inappropriate to substitute for the minor’s judgment, courts may instead employ the best interest doctrine as a means of making medical decisions on behalf of the minor.61

\textbf{C: Under the U.S. Constitution, the countervailing state interests are primarily protected through employing additional procedural safeguards and a heightened standard of proof.}

The Supreme Court of the United States acknowledged in \textit{Cruzan v. Dir., Missouri Dep’t of Health}63 that it may be inferred, from its prior decisions, the principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment.64 This “liberty interest” protected under the Due Process Clause of the Fourteenth Amendment is not an absolute right, and therefore, is subject to a balancing of an individual’s interests against the relevant state’s interests.65 \textit{Cruzan} highlights the constitutional power reserved to the state to establish a procedural safeguard to protect an individual who is now incompetent against the erroneous risk of deprivation of life.66 While the spirit of \textit{Cruzan} dances in the background of many state

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57 Wright, \textit{supra} note 35, at 37; \textit{see} Troxel, 530 U.S. at 68-69 (2000).
58 Wright, \textit{supra} note 35, at 37; \textit{see} Parham, 442 U.S. at 603 (citing Wisconsin v. Yoder, 406 U.S. 205, 230 (1972); Prince v. Massachusetts, 321 U.S. 158, 166 (1944), \textit{reh’g denied}, 321 U.S. 804 (1944)).
59 Wright, \textit{supra} note 35, at 37.
60 \textit{Id.}
61 \textit{See infra} Part V B.
62 Wright, \textit{supra} note 35, at 37.
64 Wright, \textit{supra} note 35, at 38; \textit{see} Cruzan, 497 U.S. at 283.
65 Wright, \textit{supra} note 35, at 38; \textit{see} Cruzan, 497 U.S. at 283.
66 Wright, \textit{supra} note 35, at 38; \textit{see} Cruzan, 497 U.S. at 283 (holding that a clear and convincing standard of proof was not unconstitutional).
and federal opinions, the decision whether life-sustaining treatment may be withdrawn from an incompetent individual remains a highly fact-specific inquiry under applicable state law. That is, the effect of the Supreme Court side-stepping the issue of whether substantive, as opposed to merely procedural, due process rights guarantee the right to refuse medical treatment, was the proliferation of state statutes and state rules of decision. Likewise, although Cruzan set forth the “right to die” in cases where an individual was once competent, but is now incompetent, under the framework of substituted judgment doctrine, many courts have extended this principle in cases where an individual was never competent (either by virtue of age or disability), under a similar framework.

Just how far the right to refuse medical treatment extends is unclear; however, the Court has recognized a distinction between letting a patient die and making that patient die. Clearly, there is no constitutional right to hasten death through physician-assisted suicide. Moreover, Washington v. Glucksberg confirmed that a state could make assisting suicide a crime, although committing suicide is no longer a crime in any state. Notably, Glucksberg enumerated four distinct legitimate state interests in Washington’s assisted-suicide ban. First, the state has an “unqualified interest in the preservation of human life.” Second, the state has an interest in protecting the integrity and ethics of the medical profession. Third, the state has an interest in protecting vulnerable groups—including the poor and disabled—from abuse, neglect, and mistakes. Fourth, and finally, the state may fear that permitting assisted suicide will start it down the path to voluntary and perhaps even involuntary euthanasia. In summary, the countervailing interests of the state render the right to refuse medical treatment, especially in the case of a seriously ill infant, vulnerable to attack. The primary mechanism for protecting the state’s interest is satisfied through employing additional procedural safeguards and heightening the standard of proof required prior to implementing the questionable medical treatment decision.

57 Wright, supra note 35, at 38.
58 Id.
62 Glucksberg, 521 U.S. at 728.
63 Id. at 731.
64 Id. at 731-32.
65 Id. at 732-33.
D: In regards to procedural due process under the Fourteenth Amendment to the U.S. Constitution, the relevant inquiry is, "How much process is due?" If Parham v. J.R. is controlling, then "some kind of inquiry by a neutral factfinder" may satisfy due process requirements without holding a formal or informal judicial hearing.

Critics of Cruzan rightfully question, "Is there a substantive due process right to refuse medical treatment?" The ambiguous language in Cruzan left this question unanswered. Rather, Cruzan sets forth the notion that procedural safeguards are fundamental to prevent the erroneous deprivation of life. Similarly, Comm'r, Dep't of Human Res. of Georgia v. J.R is instructive in its treatment of how procedural safeguards apply to minors, regarding the right to refuse medical treatment, namely civil commitment to a mental institution.

In Comm'r, Dep't of Human Res. of Georgia v. J.R, minor children brought a class action alleging that they had been deprived of their liberty without procedural due process by virtue of Georgia mental health laws which permit voluntary admission of minor children to mental hospitals by parents or guardians. After ruling that Georgia's law was consistent with constitutional guarantees, the Court held that "the risk of error inherent in the parental decision to have a child institutionalized for mental health care is sufficiently great that some kind of inquiry should be made by a "neutral factfinder" to determine whether the statutory requirements for admission are satisfied."
Accordingly, the inquiry must satisfy three criteria: first, a historical review must probe the child’s background using all available sources of information and include an interview with the child; second, the decision maker must necessarily have the authority to refuse to admit any child who does not satisfy the medical standards; finally, the child’s continuing need for treatment must necessarily be reviewed by a similarly independent procedure. 84

Although a state is free to require a formal or quasi-formal hearing, due process is not violated by use of informal traditional medical investigative techniques. 85 “What is best for a child is an individual medical decision that must be left to the judgment of physicians in each case.” 86 The Court further reasoned that although it acknowledged the fallibility of medical and psychiatric diagnosis, “[w]e do not accept the notion that the shortcomings of specialists can always be avoided by shifting the decision from a trained specialist using the traditional tools of medical science to an untrained judge or administrative hearing officer after a judicial-type hearing.” 87

The Comm'r, Dep't of Human Res. of Georgia v. J.R procedural safeguards are routinely applied, though infrequently accredited, to medical treatment decisions involving seriously ill infants. First, the physician's historical review of the infant includes a complete medical history, social/family history, diagnosis, treatment intervention, prognosis, assessment of family values, preferences, and at times, the involvement of social services or an institutional ethics committee. Second, the physician, as decision maker, maintains authority to refuse the withdrawal or withholding of any medical treatment which is inconsistent with the medical standard of care. Third, the infant’s need for medical intervention is reassessed by an independent procedure; that is, the infant is re-evaluated, new tests administered, changes to the plan

Mathews v. Eldridge, 424 U.S. 319, 335 (1976)) (assuming the existence of a protectible liberty interest, the Supreme Court has required a balancing of three factors:

First, the private interest that will be affected by the official action; second, the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any, of additional or substitute procedural safeguards; and finally, the Government's interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirement would entail.

Here, “some kind of inquiry” was sufficient to satisfy due process).

84 Wright, supra note 35, at 39; see Parham, 442 U.S. at 607.
85 Wright, supra note 35, at 39; see Parham, 442 U.S. at 607.
86 Parham, 442 U.S. at 607.
87 Id. at 608.
of care are made, new orders written, and other specialists are consulted in an ongoing manner with seriously ill infants.

Under the Parham standard, due process is not violated by the use of informal traditional medical techniques, such as these. To be sure, the risk of erroneous deprivation is much greater in the case of an infant; however, the design of this multifactor balancing test accounts for this difference. That is, the facts and circumstances of each particular case, along with the gravity of the deprivation, are given due weight and balanced accordingly under this test. In reality, most health care decisions involving seriously ill infants are made everyday under a Parham-like standard and are never subjected to judicial review. However, a formal or quasi-formal hearing is available by petitioning either the local probate or juvenile court of jurisdiction, as an additional safeguard.

In summary, judicial deference evidenced through requiring merely informal procedural safeguards to protect infants is rational for three reasons. First, the court legitimately defers to experts in the field of pediatric specialists to determine the validity and efficacy of whether to withdraw or withhold medical treatment. Second, physicians and parents remain continuously accountable to the courts and society at large through a complex regulatory scheme of federal and state child abuse and neglect statutes. Third, the courts recognize the privilege of the physician-patient relationship by respecting the private, delicate, and complex nature of life and death decisions.

Part II: Rights and Interests Protected under Federal Statutes:

A: Deference to medical judgment is alive and well under the Child Abuse Amendments, but is deference dead under EMTALA? Deference to medical judgment, as intended by Congress, is emblematic of the respect accorded to the private nature of the physician-patient relationship. Deference operates to limit unwarranted governmental intrusion into its citizen's private medical affairs.

The United States Congress has enacted laws specifically governing the protection and care of infants with life-threatening conditions, through the Child Abuse Amendments of 1984, pursuant to its authority under the Spending Clause.88 The

amendment defines the term “medical neglect” as the failure to provide adequate medical care within the context of the definitions of “child abuse and neglect” set forth in the Act,99 which has been expanded to expressly include the “withholding of medically indicated treatment from a disabled infant with a life-threatening condition.”90 The term “withholding of medically indicated treatment” is defined as:

[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 any of the following circumstances apply: (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) 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.91

The statute covers “infants” less than one year of age unless any issue of medical neglect involves a child older than one year who has been receiving continuous treatment or has a long-term disability.92 To qualify for a basic state grant under the Child Abuse and Neglect Prevention and Treatment Act [hereinafter CAPTA], a state must have programs, procedures, or both, in place within the state’s child protective services system for the purpose of responding to reports of medical neglect.93 Because the conditional spending eligibility criteria require states to implement state regulations, the large majority of cases implicating the Act are decided on state law grounds under each state’s child protective services statute, rather than under the federal statute.94

The statute evinces deference to medical judgment in two ways. First, the express language of the statute creates deference to reasonable medical judgment as enumerated in three medical situations.\(^9\) Second, because the term to be defined in the statute is "withholding of medically indicated treatment,"\(^9\) decisions regarding the withholding of medical treatment not indicated by the infant's condition are not governed by the statute. Rather, when treatment is not medically indicated, based upon the prevailing medical standard of care, the common law recognizes deference to medical judgment. When a physician, supported by a concurrent opinion of independent peers, determines that a particular course of medical treatment is not indicated, judicial compulsion to provide such treatment is illegitimate. Usurpation of sound medical judgment exceeds the bounds of legitimate action by a court that lacks the necessary expertise on which to formulate a contrary medical opinion. In summary, the purpose and effect of this federal statute embodies legislative and judicial deference to medical judgment, with procedural safeguards afforded through state child protection agencies.

The United States Congress has afforded more general protection for any patient, who seeks treatment through a hospital emergency room under the federal Emergency Medical Treatment and Labor Act.\(^9\) EMTALA was enacted in response to widespread "patient dumping," a practice in which patients would be transferred from one hospital's emergency room to another's for admission.\(^9\) This Act applies only to hospitals that accept payment from Medicare and operate an emergency department.\(^9\) The statute has two major requirements. First, the hospital must give the patient an "appropriate medical screening" upon presentation at the hospital's emergency department and determine whether the patient has an emergency medical condition.\(^9\) Second, the hospital must stabilize the patient prior to transfer, if transfer is necessary.\(^9\) The statute allows a patient to bring a civil suit for damages, for an EMTALA violation, against a participating hospital; however, no section permits an individual to bring a similar action against a treating physician.\(^9\) Instead, an enforcement action against a physician may be brought by the Department of Health and Human Services to bar

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\(^9\) Id.
\(^9\) Id.
participation in federal health care spending programs and or seek administrative sanctions including civil monetary penalties. Therefore, this statute does not appear to create an implied private right of action against a physician, individually. Rather, the action will lie only against the health care entity.

In the landmark EMTALA case involving seriously ill newborns, *In re Baby "K"*, the Fourth Circuit examined its application to the emergency treatment decision of an anencephalic infant who was repeatedly brought to the hospital in respiratory distress. The Hospital instituted an action against Ms. “H” and Baby “K,” seeking a declaratory judgment that it was not required under EMTALA to provide treatment other than warmth, nutrition, and hydration to Baby “K.” Two questions arose regarding the construction and interpretation of the Act: first, whether the statute created an exception for cases in which the physician determines that provision of emergency “stabilizing” treatment is medically or ethically inappropriate; and second, whether a physician’s medical judgment, protected under Virginia’s law, was in actual conflict with this federal statute, resulting in preemption of state law.

First, the Court reasoned that in the absence of express statutory language or legislative history to create an exception to the duty to provide stabilizing treatment, the “plain language” of the statute required physicians to provide treatment, regardless of the moral and ethical inappropriateness of treatment under the prevailing standard of medical care. The Court, in effect, ruled that no exception existed, even impliedly so, for a physician to use his superior skills and training to determine in his medical judgment whether the delivery of “stabilizing” care is indicated under the individualized circumstances of a particular patient’s health condition.

Second, regarding preemption, a Virginia law entitled the Health Care Decisions...
Act (HCDA) provides that "[nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate.]" Upon finding no express exception under EMTALA for medically and ethically inappropriate treatment, but finding an express provision under Virginia’s HCDA for medically and ethically inappropriate treatment, the Court found the federal and state statutes were "directly" in conflict. This finding, however, was not supported by typical preemption analysis of direct conflicts. Notwithstanding, the Court concluded that EMTALA preempted this "inconsistent" provision of state law, authorizing physicians to refuse to give such care as they determine to be medically or ethically inappropriate.

The Fourth Circuit’s interpretation of congressional intent, statutory construction and the scope of federal preemption led to a result in which “legislative” paternalism controls the hand of a physician through compelling the provision of “stabilizing” medical treatment to every medically unstable person who enters the emergency room, regardless of the patient's medical diagnosis and prognosis. While life-sustaining procedures are “ordinarily mandatory,” they may become a matter of medical discretion in the context of administration to persons in extremis. Many physicians have refused to inflict an undesired prolongation of the process of dying on a patient in an irreversible condition, when it is clear that such “therapy” offers neither human nor humane benefit. The fulcrum, upon which the decision turns, therefore, is the prognosis of the patient, not the location in which medical treatment is delivered.

Undeniably, the Fourth Circuit inferred that the United States Congress sought to supplant its judgment for that of a medical doctor under emergency circumstances. On the contrary, Congress clearly did not intend either to create a medical standard of care or insert itself into the private patient-doctor relationship. The exercise of medical judgment in accord with the prevailing standard of medical care in making individualized treatment decisions is the bedrock of American medicine, and represents a principle recognized at common law. Moreover, as a matter of statutory construction, the

109 Id. at 597 (citing VA. CODE ANN. § 54.1-2990 (Michie Supp. 1993)).
110 Id.
111 Id.
114 Id.
Legislature is presumed to create new law against the backdrop of existing law; that is, Congress has presumed knowledge of deference to medical judgment regarding medical and ethical futility. In this light, statutory silence is more appropriately interpreted as acceptance of an implied exception for medical and ethical futility than an implied exclusion to exercise medical judgment. Furthermore, the primary purpose of EMTALA is to prevent "patient dumping" through transfers from private hospitals to state-funded hospitals without first stabilizing the patient. To maintain that every person who enters an emergency room must receive life-saving treatment regardless of the circumstances, when no patient transfer issue arises, is indeed an overly-broad interpretation of Congress' protective purpose under EMTALA.

In summary, the Fourth Circuit's evisceration of medical judgment from the emergency room is difficult to reconcile with judicial deference otherwise accorded to medical judgment demonstrated through the Child Abuse Amendments, state statutory law, and our common law tradition. The duty to exercise medical judgment is not a wavering standard dependent upon which location of the hospital medical care is delivered. To hold otherwise allows a physician to withhold life-saving treatment on the neonatal intensive care unit based upon sound medical judgment under the prevailing standard of care, but requires a physician to provide life-saving treatment in the emergency room on the same infant against medical judgment on grounds of legislative mandate.

[The]he standard of conduct becomes one of 'good medical practice,' which is to say, what is customary and usual in the profession... [T]he medical profession... [has] the privilege... of setting their own legal standards of conduct, merely by adopting their own practices. [] Another explanation, perhaps more valid, is the healthy respect which the courts have had for the learning of a fellow profession, and their reluctance to overburden it with liability based on uneducated judgment.


117 In re Baby "K," 16 F.3d 590 (4th Cir. 1994).
Part III: Rights and Interests Protected under State Constitutional Law:

A: Most states have held, at a bare minimum, that the rights and protections afforded under the U.S. Constitution are similarly held as fundamental rights under their respective state constitutions.

In so finding, the state courts achieve three primary purposes; that is, the courts may expand those fundamental rights and protections afforded to their citizens, enunciate the policies and preferences of their state, and insulate their opinions from federal judicial review. In summary, even where a litigant raises a question under the U.S. Constitution, a state court largely controls whether its opinion is subjected to federal review inasmuch as it decides whether its decision is rooted in state constitutional law versus federal constitutional law.

Part IV: Rights and Interests Protected under State Statutory Law:

A: Informed Consent: Parents who wish to withdraw or withhold life-sustaining medical treatment against medical advice will not be accorded a post hoc remedy under informed consent doctrine where exigent circumstances create an exception, where there exists no viable treatment alternative and death will result without treatment, and where an accurate prognosis is unknowable even if treatment is administered.

From time to time, distraught parents have brought informed consent actions against a physician for providing emergency resuscitative treatment to their premature newborn that survived, but suffers from disabilities resulting from or related to premature birth. To be clear, these informed consent actions do not allege negligent acts regarding the care provided, rather the nature of the complaint alleges that the physician was under a duty to provide information about the medical condition of the infant, review alternative treatment options, and then obtain parental consent before delivering life-saving resuscitation.

In Montalvo, Emanuel was born at twenty-three and one half weeks upon emergency caesarean section after an unsuccessful attempt to halt premature labor. Emanuel received life-saving resuscitation upon his birth without parental consent, but

119 Montalvo, 647 N.W.2d at 416.
had developmental disabilities related to premature birth. The Montalvo complaint was dismissed for failure to state a claim, and affirmed in a three-part holding.

First, the Court held that informed consent doctrine only comes into play when there is a need to make a choice of available, viable alternatives; that is, there must be a choice that can be made. The Court reasoned that requiring informed consent here presumes that a right to decide not to resuscitate the newly born child or to withhold life-sustaining medical care actually existed. Wisconsin, in reliance on Cruzan, has refused to extend the right to refuse medical treatment beyond cases where the patient is in a persistent vegetative state. Additionally, Wisconsin has refused to allow surrogate decision-makers to assert that it is in the patient's best interest to withhold or withdraw treatment unless the patient is in a persistent vegetative state. As such, the parents had no right under state law, and similarly had no right under the federal Child Abuse Amendments to withdraw or withhold immediate post-natal care. Therefore, the Court concluded that informed consent was not required because no viable alternative to life-saving resuscitation existed.

Second, the Court held life-saving resuscitation efforts performed by a physician on a prematurely born baby fell within the exception to informed consent law. This exception rendered disclosure unnecessary in emergencies where failure to provide treatment would be more harmful to the patient than treatment.

Third, as a matter of public policy, the State's interest in preserving life was of paramount significance, and as a result, there was a presumption that continued life is in the best interests of a patient. The value judgment that life with a certain disability is "worse than death" has unending implications. Furthermore, under EMTALA, a hospital can be sued for failure to resuscitate a baby even when the physician feels the

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120 Id.
121 Id. at 421.
122 Id. at 418.
123 Id.
124 Id.
125 Id.
126 Id.
127 Montalvo, 647 N.W.2d at 418.
128 Id. at 420.
129 Id.
130 Id. at 421.
131 Id.
baby is not viable.\textsuperscript{132} It follows that if physicians can be sued for resuscitating a baby when it is viable under informed consent doctrine, and for failing to resuscitate a baby under EMTALA, physicians are placed in a continual “damned if you do, damned if you don’t” dilemma.\textsuperscript{133} Such a “lose-lose” enigma violates public policy.\textsuperscript{134}

In further refining the parents’ right to refuse informed consent and withhold life-sustaining treatment, \textit{Miller v. HCA} clarifies that parental consent to emergency treatment of a premature newborn may not be refused \textit{prior to} birth, because an informed opinion regarding the child’s medical status and alternative treatment procedures cannot be obtained until the child is born and undergoes medical evaluation.\textsuperscript{135} The parents in \textit{Miller} were informed that if their twenty-three week old infant was born alive, she would most probably suffer severe impairments, including cerebral palsy, brain hemorrhaging, blindness, lung disease, pulmonary infections, and mental retardation.\textsuperscript{136} The parents wanted no heroic measures performed on their daughter; rather, they wished nature to take its course.\textsuperscript{137}

Sidney Ainsley Miller was born alive, but suffering from respiratory distress. Although blue in color and limp, she gasped for air, spontaneously cried and grimaced.\textsuperscript{138} Life-saving respiratory support was provided under this emergent circumstance because the baby had a reasonable chance of living; that is, the prognosis for at least some infants at her gestational age and birth weight was to “go on and do well.”\textsuperscript{139} Unfortunately, as is not uncommon for premature infants, Sidney suffered a spontaneous hemorrhage several days after her birth.\textsuperscript{140} Her parents brought a battery and negligence action predicated on their refusal to give informed consent for any life-saving treatment provided to Sidney.\textsuperscript{141}

The Court held that the parents’ pre-delivery refusal of consent to life-sustaining treatment was inoperative because the neonatologist could not make an

\textsuperscript{132} \textit{Id.}
\textsuperscript{133} \textit{Id.}
\textsuperscript{134} \textit{Id.}
\textsuperscript{135} \textit{Miller v. HCA}, Inc., 118 S.W.3d 758 (Tex. 2003).
\textsuperscript{136} \textit{Id.} (mother had a life-threatening infection herself which required the doctors to induce delivery. The infant had little chance of being born alive).
\textsuperscript{137} \textit{Id.} at 762.
\textsuperscript{138} \textit{Id.} at 763.
\textsuperscript{139} \textit{Id.}
\textsuperscript{140} \textit{Id.}
\textsuperscript{141} \textit{Id.}
informed assessment of the infant’s condition until after birth. Upon birth, the infant required emergency medical treatment. The Court further held that the emergent circumstance exception to a claim for battery or negligence arises when there is no time to consult the parents or seek a court order, where the withholding of emergency treatment would result in death of the child.

Another refinement to the informed consent doctrine clarifies that parents may not refuse medical treatment merely because an accurate prognosis of the precise extent of their child’s injury and related disabilities is unknowable if, in some cases, the child’s problems are ameliorated through providing treatment. In Iafelice v. Zarafu, the parents of a child suffering from catastrophic brain injury brought a wrongful life action, predicated on failure to provide informed consent, for failure to disclose the possible severity of her disability if she survived a life-saving shunt operation to relieve swelling in her brain. The parents asserted that had they been informed, they would have withheld their consent and allowed Renee Iafelice to die.

Informed consent is predicated on the duty of a physician to disclose to his patient information that will enable him to evaluate knowledgeably the options available and the risks attendant upon each, before subjecting that patient to a course of treatment. Under the doctrine, the patient who consents to an operation is given the opportunity to show that the surgeon withheld information concerning “the inherent and potential hazards of the proposed treatment, the alternatives to that treatment, if any, and the results likely if the patient remains untreated.”

The mistaken premise in the Iafelice action is that allowing the child to die untreated was a legally viable alternative. The parents were informed of the potential for neurological deficits, but pinpointing a prognosis of their child’s degree of neurological impairment was not feasible based upon neonatal examinations and the

\[\text{\small 142 Id. at 769.}\]
\[\text{\small 143 Id. at 768.}\]
\[\text{\small 144 Iafelice v. Zarafu, 534 A.2d 417 (N.J. Super. 1987); see also Iafelice v. Luchs, 501 A.2d 1040, 1042-43 (N.J. Super. Ct. 1985) (at the age of four weeks, the child was diagnosed with intraventricular hemorrhage and secondary hydrocephalus. It is undisputed that untreated hydrocephalus causes increasing head size, intracranial pressure, brain damage, and death).}\]
\[\text{\small 145 Iafelice, 534 A.2d at 417-18.}\]
\[\text{\small 146 Id. at 418 (citing Canterbury v. Spence, 464 F.2d 772, 780 (D.C. Cir. 1972), cert. denied, 409 U.S. 1064 (1972)).}\]
\[\text{\small 147 Id.}\]
\[\text{\small 148 Id.}\]
extent of the hemorrhage alone.149 The Court found no support for the belief that a newborn child may be put to death through benign neglect on the mere expectation that she will, in some unquantified way, be a "defective" person.150 The Court underscored the State's interest in concluding, "It is life itself that is jealously safeguarded, not life in a perfect state."151

In summary, a court's dismissal of a cause of action or directed verdict against a plaintiff as a matter of law on an informed consent claim operates as a post hoc negation of parents' asserted right to withhold or withdraw medical treatment against medical judgment. Parents shall not be rewarded by way of tort damages for refusing medically indicated treatment for their infant's condition.

In addition to informed consent, which frequently forms the basis of a statutory state law claim, several other state statutory schemes may tangentially affect a court's decision-making process regarding the right to withhold or withdraw medical treatment from an infant. To briefly summarize those statutes, most if not all states have enacted some version of the following: Uniform Health Care Decisions Act, Advanced Directives, Living Wills and Health Care Power of Attorney, Medical Practice Act, Uniform Determination of Death Act, Uniform Anatomical Gift Act, Juvenile Code, and Criminal Code.152 The wide degree of variation in the codification of these statutes requires a state-specific examination to determine the applicability of such law to a given case.

Part V: Rights and Interests Protected under State Common Law:

A: Substituted Judgment: Where the parents are in agreement with the physician's medical judgment regarding withholding or withdrawing medical treatment from an infant, a reviewing court appropriately employs the doctrine of substituted judgment.

The doctrine of substituted judgment developed to facilitate judicial decision-making in cases where individuals who were once competent became incompetent

149 Iafelice v. Luchs, 501 A.2d at 1043 ("here the neonate suffered a grade three hemorrhage; therefore, the chance for a normal outcome will be at least 50% whether or not hydrocephalus accompanies the hemorrhage").

150 Iafelice v. Zarafu, 534 A.2d at 418.

151 Id. (quoting Berman v. Allan, 404 A.2d 8 (N.J. 1979)).

152 See, e.g., CA PENAL CODE § 187(a)(b) (2005) (homicide statute may or may not include "fetus").
through age, mental illness, or other disability. The doctrine has subsequently been extended to apply to cases in which an individual was never competent. Despite the inherent difficulty in substituting the judgment of a person who never possessed the capacity to exercise judgment, the doctrine is faithfully employed in many jurisdictions to "afford incompetent persons the same right as competent individuals to refuse medical treatment." In other words, the thrust of the doctrine is to promote patient autonomy. Therefore, an incompetent individual's right to refuse medical treatment can be effectuated through the doctrine of substituted judgment.

In making a substituted judgment determination, the court "dons the mental mantle of the incompetent" and substitutes itself as nearly as possible for the individual in the decision-making process. The court does not decide what the best decision is, necessarily, but rather what decision would be made by the incompetent person if he or she were competent. In determining what the incompetent person's choice would be, the judge should consider: (1) the patient's expressed preferences, if any; (2) the patient's religious convictions, if any; (3) the impact on the patient's family; (4) the probability of adverse side effects from the treatment; and (5) the prognosis with and without treatment. The judge must also "take[e] into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person." The judge should also consider any countervailing state interests, which may include: (1) the preservation of life; (2) the protection of innocent third parties; (3) the prevention of suicide; and (4) the maintenance of the ethical integrity of the medical profession.

In Ex rel. Beth, the court applied substituted judgment doctrine where the Department of Social Services, acting as legal guardian, petitioned the court for a DNR

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153 Wright, supra note 35, at 40; see In re Eichner, 420 N.E.2d 64 (N.Y. 1981); see also Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626 (Mass. 1986); In re Conroy, 486 A.2d 1209 (N.J. 1985); In re Martin, 538 N.W.2d 399 (Mich. 1995).
154 Wright, supra note 35, at 40.
155 Wright, supra note 35, at 40; see In re L.H.R., 321 S.E.2d 716, 718-19 (Ga. 1984); see also John F. Kennedy Mem'l Hosp., Inc. v. Bludworth, 452 So.2d 921 (Fla. 1984); In re Barry, 445 So.2d 365 (Fla. Dist. Ct. App. 1984).
156 Wright, supra note 35, at 40.
158 Wright, supra note 35, at 40; see Ex rel. Beth, 587 N.E.2d at 1377, 1381.
159 Wright, supra note 34, at 40; see Ex rel. Beth, 587 N.E.2d at 1377, 1381.
160 Wright, supra note 34, at 40; see Ex rel. Beth, 587 N.E.2d at 1377, 1381.
162 Wright, supra note 34, at 40; see Ex rel. Beth, 587 N.E.2d at 1381.
The child, Beth, sustained a severe brain injury in an automobile accident, which left her in an irreversible coma, commonly called a PVS (persistent vegetative state). Beth lacked cerebral cortex brain function, also called "higher brain death," but maintained some brain stem function. The Court held that evidence supported a finding that the child would choose to decline resuscitative medical treatment in the event of respiratory or cardiac arrest, and therefore, entered the DNR order. In a different case, the Supreme Judicial Court of Massachusetts declared that "[b]y requiring a court to ascertain as nearly as possible the incompetent person's 'actual interests and preferences,' the doctrine of substituted judgment seeks to ensure that the personal decisions concerning the conduct of individual affairs remain, to the greatest extent possible, with the individual." In this

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[a] 'no code' order, given on behalf of a terminally ill patient and implemented by his attending physician, is placed in the patient's medical record and directs a hospital and its staff not to apply extraordinary intrusive resuscitative measures in the event of cardiac or respiratory failure. The terminology derives from the development in recent years, in acute care hospitals, of specialized 'teams' of doctors and nurses trained in the administration of cardiopulmonary resuscitative measures. If a patient goes into cardiac or respiratory arrest, the nurse in attendance causes a notice to be broadcast on the hospital's intercommunications system giving a code word and the room number. The members of the code team converge on the room immediately from other parts of the hospital.

164 Ex rel. Beth, 587 N.E.2d at 1378 (the child cannot see, hear, or engage in any purposeful movement. Her ability to breathe on her own is extremely limited; she requires a ventilator support. She is fed through a feeding tube permanently inserted in her stomach. She experiences esophageal reflux, despite surgical intervention, where she aspirates food into her lungs and has required resuscitation. She runs the risk of future cardiorespiratory arrests).


166 Ex rel. Beth, 587 N.E.2d at 1379.

167 Ex rel. Beth, 587 N.E.2d at 1383; see also In re Conroy, 486 A.2d 1209 (N.J. 1985) (lifesustaining treatment may be withheld or withdrawn from a patient who was once competent but now incompetent if either of two "best interest" tests is satisfied—limited objective or pure-objective test). But see In re Jobes, 529 A.2d 434 (N.J. 1987) (Conroy rule does not apply in case of PVS patient, substituted judgment applies).

168 See Wright, supra note 35, at 40; see also Custody of a Minor, 434 N.E.2d 601 (Mass. 1982).
way, the free choice and moral dignity of the incompetent person are recognized. In *Custody of a Minor*, the Massachusetts Court examined the propriety of a “no code” order on an abandoned infant, in the care and custody of the state DSS (Department of Social Services), diagnosed with a terminal incurable cardiac condition, and a prognosis of one year life expectancy with or without treatment. The Court enumerated a list of factors to consider under substituted judgment doctrine when the issue presented is a “no code” order: (1) the extent of impairment of the patient’s mental faculties; (2) whether the patient is in the custody of a state institution; (3) the prognosis without the proposed treatment; (4) the prognosis with the proposed treatment; (5) the complexity, risk and novelty of the proposed treatment; (6) its possible side effects; (7) the patient’s level of understanding and probable reaction; (8) the urgency of the decision; (9) the consent of the patient, spouse, or guardian; (10) the good faith of those who participate in the decision; (11) the clarity of the professional opinion as to what is good medical practice; (12) the interests of third persons; and (13) the administrative requirements of any institution involved. The Court held the “no code” order was valid upon finding that this child will not live past his first birthday; furthermore, a “full code” would involve a substantial degree of bodily invasion, accompanied by discomfort and pain, and would do nothing but prolong the child’s agony and suffering. The

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169 See Wright, supra note 35, at 40; see also *Custody of a Minor*, 434 N.E.2d at 608 n.10 (court found slight distinction in applying best interest test in that the “inquiry is essentially objective in nature, and the decisions are made not by, but on behalf of, the child.” But, “[a]s a practical matter the criteria to be examined and the basic applicable reasoning are the same.” Under either theory, the result was the same in this case).

170 *Custody of a Minor*, 434 N.E.2d 601.

171 Id. at 608 (quoting *In re Spring*, 405 N.E.2d 115 (Mass. 1980)).

172 Id. at 608 n.9.

According to expert testimony in the Juvenile Court, resuscitation efforts, in the event of the child’s cardiac arrest, would be highly intrusive. The judge found that “[t]he institution of a full code order, replete with heroic medical life-saving techniques (i.e. intracardial medication and massage, as well as electric shock therapy) involves a substantial degree of pain and discomfort. It is indeed a substantial invasion of one’s body. Medical testimony confirms that the child presently experiences sensation and pain while supported by a respirator-ventilator. To inflict such an invasive and traumatic series of treatments on the already terminally ill four month old infant with but a few months at most to live, would be futile... The side effects of such a Full Code could result in further weakened condition, substantial pain, and possible neurological [and] liver damage” (internal citations omitted).
Court distinguished *Custody of a Minor* from traditional "right to life" cases, concluding this "question is not of life or death but the manner of dying and what 'measures are appropriate to ease the imminent passing of an irreversibly, terminally ill patient in light of the patient's history and condition." 173

The principle of autonomy declares that each person is in control of his own person. 174 "This principle, in its purest form, presumes that no other person or social institution ought to intervene to overcome a person's desires, whether or not those desires are 'right' from any external perspective." 175 In contrast, the principle of beneficence declares that what is best for each person should be accomplished. 176 The principle incorporates both the negative obligation of non-malefassence, or *primum non nocere* which translated means "first of all, do no harm," as well as the positive obligation of beneficence, to do that which is good. As a general rule, most courts recognize the principle of autonomy as the first principle of medical ethics. 177 Beneficence is generally applied only when autonomy is impossible to apply, where the patient is an infant who has not developed any values, wishes, or desires. 178 Therefore, substituted judgment is more akin to the principle of autonomy; whereas, best interest doctrine is more akin to the principle of beneficence. 179

While both cases described above purport to apply substituted judgment, the court's reasoning in its conclusion in *Custody of a Minor* is more consistent with facilitating the principle of beneficence than autonomy. The distinction may seem to be a minor one; however, the value-laden, personal interest-type factors examined under the substituted judgment inquiry are rooted in facilitating patient autonomy. Furthermore, when properly applied, the judgment of surrogates who know the patient is the judgment substituted to determine the patient's values and preferences, not the court's judgment per se. If an infant is in the care and custody of the state, and the values and preferences of the infant cannot be reasonably obtained from a patient surrogate, this doctrine is haphazardly applied. It follows that if facilitating autonomy is a mere legal fiction, then application of the principles of beneficence through best interest doctrine may be more intellectually honest. The distinction is simply this; under autonomy, one purports to "do what the patient would have decided to do, if she were

173 Id. at 609.
174 See FURROW ET AL., supra note 71, at 1305.
175 Id.
176 Id.
177 Id.
178 Id.
179 See infra Part V B.
able to decide” versus under beneficence, one purports to “do no harm, and do the most good for the patient who cannot decide for herself what to do.” This recognition cuts in favor of applying best interest doctrine in the case of an infant who has never possessed decisional capacity. Generally speaking, however, more courts tend to apply substituted judgment doctrine alone, or apply both doctrines to the same case where the best interest doctrine is relegated to operate merely as an additional safeguard for judicial decision-making.

B: Best Interest Doctrine: Where the parents disagree with the physician’s medical judgment regarding withholding or withdrawing medical treatment from an infant, a reviewing court appropriately employs best interest doctrine. Similarly, where the infant is a ward or in the custody of the state, regardless of whether the infant’s advocate agrees or disagrees with the physician’s medical judgment, a reviewing court appropriately employs best interest doctrine.

Best interest doctrine operates as an effective litmus test when questions arise as to whether the bundle of parental rights to decide what is best for their child, including decisions regarding the provision or withholding of medical treatment, conflicts with the child’s bundle of individual rights, including the right to life. In contrast to substituted judgment, where the court subjectively asks what the child would have wished or intended were he or she competent, best interest doctrine objectively determines what is in the “best interest” of the child. More often than not, the conflicting interest problem arises in the context of religious beliefs which prohibit certain types of medical intervention.

The U.S. Supreme Court, in Prince v. Massachusetts, found that parental

180 See infra Part V B.
181 See Wright, supra note 35, at 41.
182 Wright, supra note 35, at 41; see In re K.I., 735 A.2d 448, 455 (D.C. Cir. 1999).
183 Wright, supra note 35, at 41; see Newmark v. Williams, 588 A.2d 1108 (Del. 1991).
autonomy, under the guise of the parents’ religious freedom, was not unlimited. The Court held, “Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.” The linchpin in all cases discussing the “best interest of a child,” where a parent refuses to authorize medical care, is an evaluation of the risk of the procedure compared to its potential success.

In Newmark v. Williams, the Court considered the effectiveness of the treatment, the child’s chances of survival with and without medical care, the nature of the treatment (degree of invasiveness) and the effect on the child. “The State’s interest in forcing a minor to undergo medical care diminishes as the risks of treatment increase and its benefits decrease.” Accordingly, courts are generally reluctant to authorize medical care over parental objection when the child is not suffering from a potentially life threatening illness or condition.

To examine a case where religious convictions were not in issue, the court in In re K.I. applied the best interest doctrine upon adjudication of child neglect, where the guardian ad litem requested a “no code” order for a premature infant in a comatose state. The District of Columbia Court of Appeals held that in cases involving minors who have lacked, and will forever lack, the ability to express a preference regarding their course of medical treatment, and where the parents do not speak with the same voice but disagree as to the proper course of action, the best interests of the child standard

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185 Wright, supra note 35, at 41; Newmark v. Williams, 588 A.2d 1108, 1116 (Del. 1991) (citing Prince v. Massachusetts, 321 U.S. 158, 170 (1944), reb’g denied, 321 U.S. 804 (1944)).
187 Wright, supra note 35, at 41; Newmark, 588 A.2d at 1108, 1117.
188 See Wright, supra note 35, at 41; Newmark, 588 A.2d at 1117-18 (Del. 1991) (child had rare form of pediatric cancer called Burkitt’s Lymphoma with the best prognosis of 40% chance of surviving for two more years if treated. “Proposed medical treatment was highly invasive, painful, involved terrible temporary and potentially permanent side effects, posed an unacceptably low chance of success, and a high risk that the treatment itself would cause his death”).
189 Newmark, 588 A.2d at 1108, 1117.
shall be applied to determine whether to issue a DNR order. The Court concluded that to impute oral or written directives as to medical matters or a value system is not only impossible in the case of an infant, to do so “violates the spirit of substituted judgment,” the purpose of which is to facilitate the incompetent patient’s autonomy. In a similar vein, the In re C.A. Court ruled that the substituted judgment test is “of limited relevance in the case of immature minors” where the minor is a ward of the state of Illinois. “If anyone’s judgment is being substituted it is that of the parents or some other person with a close interest in the child’s welfare;” otherwise, best interest doctrine is the more appropriate test.

In summary, the judiciary applies substituted judgment and best interest doctrine to medical treatment decisions in the absence of other controlling law. Each doctrine engenders advantages and disadvantages. Three primary advantages of substituted judgment doctrine include: first, patient autonomy is maximized; second, the influence of the surrogate’s own personal choice is minimized; and, third, the surrogate’s own personal values are minimized. Three primary disadvantages of substituted judgment doctrine include: first, the test is easily manipulated, and therefore, subject to fraud; second, the legal fiction lends itself to intellectual dishonesty; and, third, reliance on an expressed wish is undercut by the notion that people change their views, especially when faced with a life-threatening illness.

Likewise, there are three primary advantages of best interest doctrine which include: first, the reliance on scientific criteria, as opposed to values and preferences, is more intellectually honest; second, the objective standard adds protection against potential prejudice or bias; and, third, the limited nature of the inquiry is less susceptible to manipulation that a thirteen-factor balancing test. Three primary disadvantages of best interest doctrine include: first, the test necessarily imputes the values of others not related to the patient, which may be inconsistent with the patient’s values; second, consideration of family values and preferences are substantially diminished; and, third, acting under the guise of another’s best interest may disarm the public from questioning

192 Id. at 456.
193 See id. at 455.
195 Id.
196 Professor Michael Gerhardt, Law & Medicine class lecture at the University of North Carolina-Chapel Hill School of Law (Fall 2003).
197 Id.
198 Id.
199 Id.
In light of these advantages and disadvantages, the application of neither one test nor the other is likely to be outcome-determinative. While substituted judgment may be more appropriate in cases where the judgment, or values and preferences of loving parents can be asserted, on the one hand, and best interest doctrine may be more appropriate in cases where the parents’ values and preferences conflict with the best interests of the child, on the other hand, a more significant issue underpins this choice. That is, the choice between the principles of autonomy and beneficence. To be sure, substitute judgment doctrine is designed to facilitate autonomy; whereas, best interest doctrine is designed to facilitate beneficence. Our historical tradition strongly favors patient autonomy. Therefore, the basis for a decision to stray from this underlying principle should be acknowledged and well-reasoned; the case of an infant who has never possessed decisional capacity may be such a case as to warrant departure from this principle.

Part VI: Additional Concerns:

A: Application of a heightened evidentiary standard, such as clear and convincing proof, may be justified when guarding against the risk of erroneous deprivation of a patient who was once competent, and now rendered incompetent, but unjustified in cases where the patient was never competent.

In their efforts to remove a “no code” order in Custody of a Minor, the Department of Social Services argued that the presumption in favor of life required the application of proof beyond a reasonable doubt that the terminally ill child “would not have wished such treatment” or that the “withholding of medical treatment” is in the child’s best interest. Not persuaded, the Court ruled “[t]o require judges in reviewing medical judgments to reach a level of moral certainty (internal citation omitted) not only makes judicial approval of “no code” orders highly unlikely, but would cause those terminally ill patients involved to suffer unnecessary pain and loss of dignity.”

In contrast, the Cruzan Court reasoned that the standard of proof not only reflects the importance of a particular adjudication, but also serves as “a societal

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\textsuperscript{200} Id.
\textsuperscript{201} Custody of a Minor, 434 N.E.2d 601, 609 (Mass. 1982).
\textsuperscript{202} Id. at 610.
judgment about how the risk of error should be distributed between litigants.\textsuperscript{203} The more stringent the burden of proof a party must bear, the more that party bears the risk of an erroneous decision.\textsuperscript{204} Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment.\textsuperscript{205} As such, a state "may apply a clear and convincing standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state."\textsuperscript{206}

Application of a heightened evidentiary standard, such as clear and convincing, may be justified when guarding against the risk of erroneous deprivation of a patient who was once competent, but now rendered incompetent,\textsuperscript{207} but unjustified in cases where the patient was never competent. Because evaluating the "intentions or wishes" of a person who was never competent is purely an exercise in legal fiction, scrutinizing what the patient "said or did" to satisfy the heightened burden is a futile inquiry. Many times, the incompetent has not uttered a word or gesture indicative of their wishes regarding medical treatment and in cases where the incompetent has, such as \textit{In re A.C.}, those words may be disregarded based upon her adjudged incompetency. Instead of operating to accumulate more precise factual evidence that yields greater certainty of a patient's wishes, in cases where the patient was never competent, a heightened standard precariously operates to accumulate more value judgments and preferences that yield greater "moral certainty." Therefore, application of a heightened evidentiary standard, at least in cases where the patient was never competent, is an unjustified means to safeguard against the risk of erroneous deprivation of life.

A small minority of states, such as Missouri, may nonetheless require a clear and convincing standard even in cases where the patient was never competent. Under such circumstances, there is an alternative to employing such value-based justifications that concerned the court in \textit{Custody of a Minor}.\textsuperscript{208} Morality, to be sure, encompasses more than merely positive law. Respecting and guarding the sanctity of human life implores

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\item \textsuperscript{203} \textit{Cruzan v. Dir., Missouri Dep't of Health}, 497 U.S. 261, 263 (1990).
\item \textsuperscript{204} \textit{Id.}
\item \textsuperscript{205} \textit{Id.}
\item \textsuperscript{206} \textit{Id.} at 284.
\item \textsuperscript{207} See \textit{In re Westchester County Med. Ctr.}, 531 N.E.2d 607 (N.Y. 1988) (elderly patient, O'Connor, sustained several strokes and require placement of nasogastric tube to sustain life. O'Connor told her children she did not want to be kept alive by artificial means if unable to care for herself. Court held, "On this record there is not clear and convincing evidence that the patient had made a firm and settled commitment, while competent, to decline this type of medical assistance under circumstances such as these").
\item \textsuperscript{208} \textit{Custody of a Minor}, 434 N.E.2d 601, 608, n.10 (Mass. 1982).
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recognition of natural law as well. Truly guarding dignity and respect for life inures acceptance of first principles; that is, life naturally begins and ends. Artificially maintaining life beyond its natural end violates nature. This struggle cheapens life, stripping it of dignity and respect. Moral certainty, then, is like an instrument that must yield to natural law and allow the passing of life that has naturally ceased. Therefore, it logically follows that absent emergent circumstances where recovery is possible and merely life-preserving equipment is temporarily employed, moral decisionmaking supports the removal of life-sustaining equipment where life would have ended but for the long-term use of mechanical devices to unnaturally sustain it.

B: Judicial intervention is generally unjustified absent a difference of opinion between the treating physician and the parents. Where a third party seeks judicial intervention, a threshold finding of medical neglect necessarily precedes a court order requiring a course of treatment when the parents and physician are in agreement about withholding or withdrawing treatment.

Where a loving parent makes a decision to withhold or withdraw life-sustaining treatment which is consistent with the treating physician’s medical judgment under the prevailing standard of care, judicial intervention is unnecessary. The President’s Commission noted that decisions regarding life-sustaining treatment prior to 1975, when the courts addressed the matter in Quinlan, were routinely made by physicians and families without judicial review. The court in In re Quinlan found judicial intervention generally inappropriate, “not only because that would be a gratuitous encroachment upon the medical profession’s field of competence, but because it would be impossibly cumbersome.” The constitutional right to withhold or withdraw medical treatment is not lost because of incompetence or youth. Rather, the right of the parent to speak for the minor child is so imbedded in our historical tradition as to create a presumption that the “natural bonds of affection lead parents to act in the best interest of their children.” In a case of suspected neglect or abuse, or when the parent assumes a stance that in any way endangers the child, the parent’s right to speak for the child may

209 See generally President’s Comm’n for the Study of Ethical Problems in Medicine & Biomedical & Behavioral Research, in 1 MAKING HEALTH CARE DECISIONS : THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP (1982).
211 Id. at 718 (citing In re Quinlan, 355 A.2d 647, 669 (N.J. 1976) cert. denied, 429 U.S. 922 (1976)).
212 Id. at 722.
213 Id.
be lost. The beginning presumption, however, is that the parent has the child's best interest at heart.

Against this framework, the In re L.H.R. Court addressed the narrow question of whether dutiful parents may exercise this right on behalf of their terminally ill infant who is in a chronic vegetative state, with no reasonable possibility of attaining cognitive function. The Court held that:

the right to refuse treatment or indeed to terminate treatment may be exercised by the parents or legal guardian of the infant after diagnosis that the infant is terminally ill with no hope of recovery and that the infant exists in a chronic vegetative state with no reasonable possibility of attaining cognitive function. The above diagnosis and prognosis must be made by the attending physician. Two physicians with no interest in the outcome of the case must concur in the diagnosis and prognosis. Although prior judicial approval is not required, the courts remain available in the event of disagreement between the parties, any case of suspected abuse, or other appropriate circumstances.

Moreover, once the diagnosis is made that the infant is terminally ill with no hope of recovery and is in a chronic vegetative state, the State has no compelling interest in maintaining life. This Court concluded that:

[the decision to forego or terminate life support measures is, at this point, simply a decision that the dying process will not be artificially extended. While the state has an interest in the prolongation of life, the state has no interest in the prolongation of dying, and although there is a moral and ethical decision to be made to end the process, that decision can be made only by the surrogate of the infant.

Similarly, Florida courts have found judicial intervention unnecessary and a

214 Id.
215 Id.
216 Id. at 722-23.
217 Id. at 723.
218 Id.
Washington court found judicial intervention is rarely required.\textsuperscript{220} The \textit{In re Barry} Court pronounced, "We must remember that the conscience of society in these matters is not something relegated to the exclusive jurisdiction of the court."\textsuperscript{221}

Where an allegation of medical neglect is asserted against a parent who directs the withholding or withdrawal of life-sustaining treatment, judicial intervention is necessarily exercised through the state's \textit{parens patriae} power. The \textit{parens patriae} power derives from the inherent equitable authority of the sovereign to protect those persons within the state who cannot protect themselves because of an innate legal disability.\textsuperscript{222} \textit{Parens patriae} jurisdiction is frequently invoked in cases involving substituted consent for medical procedures.\textsuperscript{223}

In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervise parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.\textsuperscript{224} In \textit{Matter of Storar}, a state official applied for authority to continue blood transfusions to a profoundly retarded fifty-two year old patient in a state facility who suffered from terminal cancer.\textsuperscript{225} The case is instructive here inasmuch as \textit{Storar} was never competent, and permanently resided in a state facility.\textsuperscript{226} Reversing both trial and intermediate appellate courts, which upheld the refusal of the patient's mother to continue the transfusions, the New York Court of Appeals wrote:

Mentally John Storar was an infant and that is the only realistic way to assess his rights in this litigation . . . A parent or guardian has a right to consent to medical treatment of behalf of an infant (Public Health Law, § 2504, subd. 2). The parent, however, may not deprive a child of life saving treatment, however well intentioned.\textsuperscript{227}

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\item \textit{In re Colyer}, 660 P.2d 738 (Wash. 1983).
\item \textit{Id. at 1047} (\textit{parens patriae} commonly invoked when court authorizes a blood transfusion over the objection of an injured or sick child's parents); \textit{see also} \textit{State v. Perricone}, 181 A.2d 751 (N.J. 1962), \textit{cert. denied}, 371 U.S. 890 (1962); \textit{Muhlenberg Hosp. v. Patterson}, 320 A.2d 518 (N.J. Super. 1974).
\item \textit{Id.}
\item \textit{Id. at 73} (internal citations omitted).
\end{enumerate}
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Even when the parents' decision to decline necessary treatment is based on constitutional grounds, such as religious beliefs, it must yield to the State's interests, such as parens patriae, in protecting the health and welfare of the child (internal citations omitted).

Therefore, when the parent's decision may adversely affect the child's health or welfare such that the question of medical neglect is raised, judicial intervention is necessary to protect the child's interests.228

Taking a strikingly different view, the Supreme Judicial Court of Massachusetts, in Superintendent of Belchertown State School v. Saikewicz229 ruled that the "question of giving or withholding of life-prolonging treatment from incompetents must in all instances be presented to the probate court for hearing."230 Upon noting the proliferation of institutional ethics committees to inform the probate judge, the Saikewicz Court concluded, "[W]e take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent."231 The Saikewicz Court has been vociferously criticized for demonstrating "a distrust and lack of understanding of medical care procedures" through requiring what amounts to an adversary hearing and a judicial decision in every case.232 Supporters of Saikewicz, however, maintain that judicial intervention is the only mechanism for guaranteeing due process to the incompetent patient.233

Scientific and technological advances are occurring with such rapidity that they have outstripped the ability of society to develop an ethical base for dealing with problems caused by new possibilities.234 Weighing in on the Saikewicz debate, one philosopher pronounced:

Perhaps the strongest argument against abdicating to either medical professionals or legal professionals our moral responsibility is the fact that with regard to Saikewicz, various representatives of both groups

228 See id.
231 Saikewicz, 370 N.E.2d at 434.
232 See In re L.H.R., 321 S.E.2d at 720 (citing William J. Curran, The Saikewicz Decision, Law-Medicine Notes, 298 NEW ENG. J. MED. 499 (March 2, 1978)).
233 See In re L.H.R., 321 S.E.2d at 720 (citing Charles H. Baron, Medical Paternalism and the Rule of Law: A Reply to Dr. Relman, 4 AM. J. L. & MED. 337 (1978)).
234 Id. at 722.
seem so absorbed in their respective visions of professional expertise that they have been unable even to entertain the possibility of a third alternative.\textsuperscript{235}

The philosopher, Buchanan, articulated an approach for handling \textit{Saikewicz}-type cases based on three propositions: (1) the proper presumption is that the incompetent's family will make treatment decisions; (2) this presumption is defeasible if vigorous discussion and accountability through impartial review show the family's decision to be indefensible; and (3) the proper institutional framework for implementing [and evaluating the first] two propositions is an ethics committee.\textsuperscript{236} Now in widespread use, institutional ethics committees, comprised of individuals from a diverse range of professional backgrounds, primarily operate to develop guidelines and procedures to facilitate physician-family decision making.\textsuperscript{237} To a large degree, ethics committees informally mimic procedural due process safeguards implemented by courts, through employing substituted judgment and best interest doctrine.

In summary, judicial deference is justified based upon the competence of physicians, the constitutional rights of the parents, and judicial economy. Absent a difference of opinion between the treating physician and the parents or an allegation of medical neglect by a third party, judicial intervention is unnecessary. Unnecessary consumption of judicial resources constitutes waste. Properly read, the pronouncement in \textit{Saikewicz} that disputes "must in all instances be presented to the probate court for hearing," need only be exercised where an actual dispute among concerned parties exists. Routine review of every case involving the withholding or withdrawal of life-sustaining treatment would unnecessarily encumber our courts. Moreover, our adversarial system is premised upon an actual live dispute between proper parties. Routine review where no dispute exists violates justiciability doctrine, and inasmuch, amounts to nothing more than an advisory opinion of the court. The proponents' overly broad interpretation of the holding in \textit{Saikewicz} taken to its logical end, violates the judiciary's self-imposed restraint. Such restraint not only preserves the balance of power among the coordinate branches, but also dutifully serves the judiciary. Judicial economy is a great benefactor, indeed, of the prohibitions enunciated under justiciability doctrine.

\textsuperscript{235} Id. at 721 (citing Allen Buchanan, \textit{Medical Paternalism or Legal Imperialism: Not the Only Alternative for Handling \textit{Saikewicz}-type cases}, 5 Am. J. L. & Med. 97 (1979)).

\textsuperscript{236} See Id. at 721 (citing Allen Buchanan, \textit{Medical Paternalism or Legal Imperialism: Not the Only Alternative for Handling \textit{Saikewicz}-type cases}, 5 Am. J. L. & Med. 97 (1979)).

\textsuperscript{237} See id. (to some degree, ethics committees employ both the doctrine of substituted judgment and best interest doctrine).
Conclusion:

In conclusion, as this body of law continues to develop over the next several decades, the courts’ movement on two key doctrinal issues will further define parents’ right to withdraw or withhold medical treatment on behalf of their seriously ill infant. First, whether courts generally will adopt or adhere to the position that governmental intrusion, via a state advocate for the child (i.e. guardian ad litem), is to be tolerated in the absence of a threshold finding of medical neglect. Second, whether a brighter line will distinguish the application of substituted judgment versus best interest doctrine in regards to the relationship of the surrogate decision-maker to the infant. The courts’ path on both issues will undoubtedly impact family autonomy and shape health care policy.