

Chapter 42

Legal Issues in Newborn Intensive Care

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"The narrow question we must decide is whether Texas law recognizes a claim by parents for either battery or negligence because their premature infant, born alive but in distress at only twenty-three weeks of gestation, was provided resuscitative medical treatment by physicians at a hospital without parental consent." In 2003, the Texas Supreme Court affirmed the decision to overturn a \$60million verdict awarded to parents after their extremely premature daughter was resuscitated against the parents' wishes.¹

INTRODUCTION

Since the sixth edition of this textbook was published in 2004, there have been a small number of new legal decisions involving sick newborns. However, these decisions have changed the medical-legal landscape for caregivers, parents, and hospital administrations. In 2005, a disabled newborn was removed from a ventilator against the mother's wishes. While the Schiavo controversy raged in America,² the contemporaneous case of Sun Hudson went relatively unnoticed. In the case mentioned above, the Texas Supreme Court³ handed down their final decision in the case of a 23, week gestation premature infant that was resuscitated against her parents' wishes. While the number of new decisions has been limited, these rulings have served to further complicate the legal picture for the neonatal team. This chapter addresses a variety of situations in which the neonatal practitioner must be cognizant of both the medical and legal implications of the circumstances.⁴

There are a variety of transitions that take place as a fetus emerges from the birth canal or a cesarean incision. From a physiological standpoint, the newborn becomes an entity that can live separate from the mother and the placental circulation. As the fetus is undergoing this hemodynamic, pulmonary, and cardiovascular transition, a legal transition also takes place.

While there has been tremendous controversy surrounding the uncertain legal standing of a fetus, many complex issues remain to be resolved after a sick newborn is born alive and therefore has "personhood." Even after the moment of parturition, the legal standing of the newborn remains

unclear in a variety of situations. A fragile newborn whose life is complicated by extreme prematurity, congenital anomalies, severe asphyxia, or other life-threatening ailments may be viewed as a unique legal entity.⁵ These newborns clearly have more rights than a fetus. However, a number of state statutes and court cases suggest that critically ill newborns have legal standing that can be distinguished from that of healthy newborns and other "persons." There appears to be a legal gray area that the sick newborn occupies. With a growing body of conflicted civil and criminal law, the legal standing and rights of the sick newborn remain unresolved. This confusion has often left neonatal health care teams and parents in the difficult position of simultaneously dealing with a critically ill patient while trying to ascertain the legal implications of their decisions.

LEGAL CONCEPTS AND DEFINITIONS

If a baby is born alive it is generally recognized as having legal "personhood," with all of the associated rights, privileges, and consequences in civil and criminal matters. Different states have varying approaches to the definition of "live birth." Some illustrative examples follow

Live Birth

The Alabama statute states: "The complete expulsion or extraction from the mother of a product of human conception, irrespective of the duration of pregnancy, which, *after such expulsion or extraction*, breathes, or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, *whether or not* the umbilical cord has been cut or the placenta is attached. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps"⁶ (emphasis added).

The Iowa⁷ statute is quite similar to the Alabama statute. Of note, the language describing "transient cardiac

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contractions” and “fleeting respiratory efforts” was not added to the statute until 1997. The Alaska⁸ statute also has similar wording to the Alabama law. However, the Alaska statute does *not* contain the additional language concerning transient cardiac contractions or fleeting respiratory effort.

The Maine⁹ statute contains the language from the Alabama statute, but Maine adds that “Each product of such a birth is considered live born and fully recognized as a human person under Maine law.”

Statutes of most states are fundamentally similar to those listed above. Some states have explicitly added the caveat that live born is *not* related to gestational age. Other states, such as Maine, make it unmistakably clear that any baby that is live born is a “person.” The Maine statute would seem to minimize much of the confusion that takes place on the cusp of viability. However, these statutes have not been able to eliminate the controversy concerning the legal standing of critically ill newborns.

Within the context of abortion laws, the legislatures of some states, including Pennsylvania¹⁰ and Alabama,¹¹ have added language to determine whether or not an infant was “born alive.” The additional language deals with “brain wave activity.” These statutes address the specific case of a fetus being born alive after an attempted abortion. These statutes tend to criminalize physician behavior if such a live-born infant is not provided with appropriate resuscitative care. Therefore, the definition of “live birth” for the purpose of birth certificates has one set of criteria, and the definition of “born alive” for abortion statutes has additional language. Clinically, the distinction is almost meaningless because obstetricians, pediatricians, and neonatologists essentially never measure an infant’s brain wave activity in the delivery room. Since EEG measurements are rarely, if ever, used during resuscitation or to determine whether or not an infant is viable, the definition of “alive” is generally dependent upon some indication of functioning of respiratory, cardiovascular, or voluntary muscle system. It is unclear why individual states will define “live birth” or “born alive” differently in different statutes. It is also unclear why the mention of “brain wave activity” is contained in the abortion statutes and not generally contained in the Health and Human Safety (and related) codes. However, it should be noted that in the same state there can be two different definitions of whether or not an infant was ever “alive.”

For criminal law purposes, the A.L.R. has established another test of “life”. This test is the *separate and independent existence*. For purposes of homicide, the A.L.R. addressed the question of whether or not a newborn ever had “life.” Based on various court cases, the preferred test was that a showing of a “separate and independent existence” (or words to like effect) of the newborn from its mother should be made.¹²

Wrongful Life

In these cases, the plaintiff is the newborn.¹³ This cause of action, on behalf of the newborn, purports tort liability

specifically because the baby was born. These cases are often seen where a child is born with severe congenital anomalies, and it is maintained that the infant should never have been born. Some state courts say there is no rational way to compare nonexistence with impaired existence. In these states, a wrongful life cause of action is not allowed. Other courts affirm that a “less-than-perfect” life has inherent sanctity, and therefore, the life has worth. However, the sanctity of that life does not alone provide a basis for rejecting child’s tort action.¹⁴ These states would allow a wrongful life cause of action. In the *Miller* case, the Texas Supreme Court quoted the appellate court ruling that “. . . no legal or factual issue exists to decide about providing such treatment because a court cannot decide between impaired life versus no life at all.¹⁵

Wrongful Birth

In these cases, the plaintiff is the mother. This cause of action is sometimes filed after a failed sterilization procedure, when an unwanted pregnancy ensues. These cases can also arise when a child is born with congenital anomalies. The parents may maintain that the diagnosis should have been discovered early in the pregnancy so that the parents could have considered the option of pregnancy termination. Parents often seek to recover the economic costs of raising the child that resulted from the undesired, unplanned, or otherwise “imperfect” pregnancy.

INJURY PRIOR TO BIRTH

When a fetus is harmed by civil or criminal wrongdoing, the fetus may succumb to said injury prior to being born alive. In other cases, the fetus may suffer injury in utero and subsequently be born alive and become a “person.” Because the American legal system has often treated these situations differently, each scenario is individually discussed below.

If the Fetus Dies In Utero

Because fetuses in this category are never born alive, some of this material could be included in Chapter 20 of this textbook. However, in both a civil and criminal context, there is substantial legal overlap between cases where injured fetuses die in utero and cases where the injured fetus survives the birthing process.

Civil Law

Wrongful Death It is not uncommon for an obstetrician or perinatologist to be sued for negligence following a fetal death. Additionally, hospitals are often named as defendants in medical malpractice actions based on issues such as failure to diagnose, fetal monitoring, whether or not to perform a cesarean section, and timely intervention. In these situations, even though the fetus is never born alive, some states allow the estate to sue for wrongful death.¹⁶ The majority of states recognize a cause of action for

wrongful death of a fetus if the fetus was “viable” at the time of injury. These states tend to emphasize the importance of the fetus having been at a gestation that could have survived outside of the womb. However, West Virginia does *not* require that the fetus be “viable” at the time of injury, and this state allows recovery for wrongful death regardless of the gestational age of the fetus when the injury is sustained.¹⁷ Of note, California is one of the states that does not allow a wrongful death suit on behalf of a fetus that died in utero.¹⁸

Negligent Infliction of Emotional Distress Parents of a fetus that died may also be able to recover for negligent infliction of emotional distress.¹⁹ The *Dillon* criteria are (1) that the defendant’s negligence caused serious bodily injury (or death) to the victim, (2) that the plaintiff in fact witnessed the event that caused this injury, and (3) that the plaintiff experienced severe emotional distress as a result of the observation of the event.²⁰ In the case where the plaintiff is the formerly pregnant mother, the *Dillon* criteria are generally satisfied, even if the mother was asleep at the time of the supposedly negligent act or the injury.

Damages As is the case with many tort issues, there is considerable interstate variability. If the plaintiff can establish all of the elements of the essential negligence case, a recovery can be made on behalf of a fetus that was never born “alive.” The parents may be able to recover for past medical expenses. In some states, pain and suffering damages are not available after any plaintiff has died.²¹ In these states, following a fetal death, no recovery is allowed for pain and suffering that was experienced prior to the demise.

Criminal Law

For purposes of homicide, or other criminal law statutes, lawmakers have established criteria for whether or not a newborn was ever “alive.” This issue gained widespread attention in the Arizona case of *Vo v. Superior Court*.²²

On May 14, 1991 Nghia Hugh Vo, riding in a stolen car, allegedly fired two shots at a pickup truck on the freeway. The female passenger was pregnant.²³ She was struck in the head by a bullet. She died as a result of the gunshot wounds, and her fetus died in- utero. Vo was charged with two counts of murder. The court examined the possible charging of Vo with murder or manslaughter of the fetus. The court concluded that: “Legislature did not intend to include a fetus in the definition of ‘person’ or ‘human being’ contained in murder statute; thus, killing of a fetus does not constitute first-degree murder.”²⁴

The court further clarified their opinion by stating that it was the responsibility of the legislature if they intended to include a fetus in the definition of a person²⁵ for purposes of the homicide statutes. Of note, the Arizona legislature did subsequently respond by passing legislation²⁶ that expanded the definition of manslaughter to include a fetus. The classification of manslaughter included “. . . knowingly or recklessly causing the death of an unborn child at any

stage of its development by any physical injury to the mother of such child which would be murder if the death of the mother had occurred.” This broader concept of unlawful homicide expanded the legal rights of a fetus.

If the Fetus Is Subsequently Born Alive

Civil Law

In the context of civil law, the situation in which a fetus is harmed and then subsequently born alive is often quite similar to the situation in which any other person is harmed. Just because the injury is inflicted prenatally does not generally limit the civil options available to the newborn or the estate. If there is a prenatal injury resulting in a postnatal lawsuit, these suits are often directed against obstetricians and hospitals. Failure to diagnose, failure to treat, and delayed treatment are common malpractice complaints. These lawsuits are quite similar to the situation when the fetus does not survive until parturition. However, there are more causes of action and remedies available when the fetus survives to become a live-born baby. Causes of action, such as negligent infliction of emotional distress, can generally be maintained. A surviving newborn has essentially the same civil rights as any other “person.”

Wrongful Death If there is a prenatal injury, and the child is born alive and subsequently dies as a result of those injuries, a wrongful death action can be maintained. Unlike the situation when the fetus dies in- utero, there is not the same interstate variability in these cases. If the child is born alive, wrongful death suits are generally allowed.

Criminal Law

When a newborn dies as a result of criminal activity,²⁷ courts have largely refused to make a distinction based on timing of the injury. Following *Vo*,²⁸ various states adopted legislation to address the situation where a fetus is harmed in utero.²⁹

In a 2000 case, the Superior Court of Maricopa County addressed the specific problem of an in-utero injury resulting in a neonatal death. The court was faced with a defendant who shot and killed a woman who was 8½ months pregnant. The child was born and lived for one day. The prosecution argued that reckless manslaughter statutes should apply, and that the defendant would be guilty of an unlawful killing, even though the injury took place prior to parturition. The court held,³⁰ and the appellate court affirmed,³¹ that the homicide statutes apply to the killing of a child that is born alive, even if the fatal injuries were inflicted prenatally. The court further held that the statutes were not rendered impermissibly vague, and due process was not violated by applying the homicide statutes to this defendant.

EXTREMELY PREMATURE INFANTS

As noted above, if an infant is born with a heart rate, respiratory effort, or voluntary muscle movement, the baby is

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considered to be a live birth. However, this does not mean that the medical or legal issues are completely resolved. Ironically, some of the most renowned legal cases concerning newborns are brought specifically because the baby survived, and the parents had expressed their wishes that the baby not be resuscitated after birth. With respect to the tiniest newborns, “born alive” may be a state of being that lasts only seconds or minutes. Babies born during the middle part of the second trimester can be born with a spontaneous pulse and some brief respiratory effort. Technically, these babies are born alive, and therefore they are persons. Medically, the technology does not exist that can offer them reasonable assistance. Legally, these tiny entities often exist in a “gray zone.”

Complications of extreme prematurity include death, intracranial hemorrhage, retinopathy of prematurity, blindness, cerebral palsy, deafness, developmental delay, mental retardation, failure to thrive, chronic lung disease, recurrent pulmonary (and other) infections, reactive airway disease, and other severe chronic diseases.³² With improved technology has come increased survival rate for the tiniest babies. However, many authors, health care providers, and parents wonder if this increased survival comes at the unacceptable price of the substantially increased incidence of moderate- to severe handicaps.

A normal pregnancy generally lasts 40 weeks. An infant is considered to be premature when the gestation is less than 37 weeks. Birth weight less than 2500 grams is considered to be low birth weight. If a newborn weighs less than 1500 grams, this is considered to be very low birth weight, and infants less than 1000 grams are classified as extremely low birth weight. There are a variety of causes of prematurity and low birth weight including maternal hypertension, multiple gestation, and inadequate prenatal care. In many cases, the etiology is unknown. However, maternal smoking, low socioeconomic status, and African-American race have been causally linked to low birth weight.

With the advent of newer therapies and technologies including antenatal corticosteroids,³³ surfactant replacement therapy,³⁴ high frequency^{35,36} and other modes of mechanical ventilation,³⁷ and advances in all aspects of NICU care, it is not unusual for babies weighing one pound to survive.

Unfortunately, the complications of prematurity can be profound. The complications of prematurity tend to occur in the smallest and most premature babies. Although survival for extremely low birth weight babies has improved over the last 20 years, the incidence of complications is substantial. Recently published data support the notion that extremely premature infants are at high risk for long-term neurodevelopmental complications.³⁸ D’Angio et al.³⁹ shows that surviving infants less than 29 weeks gestation now have greater than a 50% of having at least one severe disability.⁴⁰ For many years it has been known that otherwise “normal” premature babies will often have subtle neurological abnormalities, such as cognitive deficits, which can be difficult to diagnose prior to the child reaching school age.

Data published in the *Journal of Perinatology*⁴¹ demonstrates improvements in survival and outcome for babies with birthweight of 500 to 800 grams. These data were compiled by the prestigious Committee on the Fetus and Newborn, a section of the American Academy of Pediatrics. In this series, the majority of newborns survived, even when the smallest babies (500–599 gram cohort) were evaluated. The majority of the babies in this study survived until discharge. As is often seen in outcome studies of extremely premature newborns, some of the complications seen in the tiniest survivors included intracranial hemorrhage, periventricular leukomalacia, abnormal tone, poor suck and swallow, seizures, abnormal EEGs, and retinopathy. Given the long-term outcome data reported by Hack et al.^{42,43} and other groups, strong concern remains among neonatal practitioners that significant challenges face the tiniest of survivors.

In this sense, new technology can be seen as a “double-edged sword.” Tiny, fragile newborns that would have likely died 15 years ago now have an improved chance of survival. However, significant and often profound complications can arise. Because long-term morbidity may not be readily apparent, there is often a staggering burden on the family and the health care team when there is the high potential for a one-pound baby to be born. Given the high likelihood of death or severe deficits, should the baby receive resuscitative efforts?

Given this background of uncertainty,⁴⁴ health care practitioners, parents, and the courts face considerable challenges in attempting to draft meaningful guidelines for the care of the smallest babies. *Roe v. Wade*⁴⁵ established the right to terminate a pregnancy under certain circumstances. However, the Justices addressed the complexities inherent in efforts to determine “when life begins”:

We need not resolve the difficult question of when life begins. When those trained in the respective disciplines of medicine, philosophy, and theology are unable to arrive at any consensus, the judiciary, at this point in the development of man’s knowledge, is not in a position to speculate as to the answer.^{46,47}

This observation may or may not be a satisfactory answer in determining the gestational age at which abortion is “allowed.” Perhaps more importantly, it does not shed light on the question of when an extremely premature infant is considered “preivable” and when the infant is considered to be deserving of full resuscitative efforts.⁴⁸

The progeny^{49,50} of *Roe* further defined the limits of the right to terminate an undesired pregnancy. In 1992, in *Planned Parenthood of Southeastern Pennsylvania v. Casey*, the court explicitly reaffirmed that the “line should be drawn at viability.”⁵¹ So, “preivable” fetuses are not accorded the same rights as fetuses that have passed 23–24 weeks gestation. Preivable is generally viewed as gestation at which the fetus is not capable of independent existence outside of the uterus. Premature fetuses that can be kept alive only with the use of technology are *not* considered to be “preivable.” Only fetuses at a gestation that could not survive with modern NICU care are considered preivable.

What if the child is born alive at 22–24 weeks gestation? In many states, the fetus could have been aborted at this gestation.⁵² However, if the child is born alive, the law may be considerably more complex.

The survival rate at 23 weeks gestation has recently reported to be in the 10–30% range, with approximately a 50% incidence of moderate or severe handicap for the survivors.⁵³ Two widely respected groups, the Committee on the Fetus and Newborn and the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network, have also published outcome data in the journal, *Pediatrics*.⁵⁴ Data, such as these recent publications, are often presented to families when they are facing the extremely difficult decision of whether or not to forgo resuscitation. Health care providers have striven to provide families with the most accurate and up-to-date information to facilitate informed decision-making.

CARING FOR PREMATURE INFANTS AGAINST PARENTS' WISHES

HCA v. Miller

On August 17, 1990, Karla Miller was admitted to an HCA Texas hospital in premature labor. Gestation was estimated at 23 weeks.⁵⁵ Because Mrs. Miller had an “infection,” the obstetrician determined that terminating the pregnancy would be unsafe for the mother. An obstetrician and neonatologist met with the Millers to discuss the poor outlook for babies delivered at this gestation. After these discussions, the Millers orally requested that no heroic measures be provided. Initially, the health care providers supported the parents' decision. However, subsequent meetings took place with the obstetrician and hospital administration. It was decided that if the baby was born alive and weighed more than 500 grams, then the baby would receive resuscitative efforts.⁵⁶

The obstetrician explained this to Mr. Miller, who again reiterated the parents' wishes that the baby not be resuscitated. The baby was born “alive,” and was resuscitated. Sidney Miller survived. She now suffers from “severe physical and mental impairments,” and it is anticipated that she will be unable to provide care for herself.⁵⁷

The Millers sued HCA (the treating hospital was a subsidiary of HCA), under a theory of vicarious liability. The parents sued because their daughter was treated without their consent, and they also asserted that the HCA hospital had vicarious liability because the hospital had a policy mandating treatment of all newborns weighing greater than 500 grams, even without parental consent. Finally, the parents asserted that HCA had direct liability because the hospital did not have policies in place to prevent this unwanted treatment of their daughter. The hospital asserted that parents had no right to refuse life-sustaining measures.

At the trial court level, the Miller's were awarded a total verdict exceeding \$60 million.⁵⁸ In overturning this verdict,

the appellate court ruled that the parents did not have the right to refuse consent for resuscitation. In making their decision, the court referred to the Advanced Directive Act. If life-supporting care is withheld or withdrawn, the Advanced Directives Act protects physicians, health care professionals, and institutions from civil and criminal liability. However, a patient must be certified as “terminal” before the health care providers are protected under the act.⁵⁹ The court ruled that the condition of Sidney Miller could not be certified as “terminal” under the Advanced Directives Act.⁶⁰ Therefore, there was no parental right to deny “. . . urgently needed life-sustaining medical treatment, and no court order was needed to overcome their refusal to consent to it.”⁶¹

In reaching their decision, the Texas Appellate Court discussed three legal issues and potentially competing interests. Each of these issues is discussed below:

1. Parents have the right to consent for their children's medical care.
2. Parents have a legal duty to provide needed medical care for their children.
3. The state has an interest in guarding the well-being of minors.

Parents' Right to Consent

In general, parents are responsible for the care, custody, and control of their children. This liberty interest is a fundamental right and it is protected by the due process clause of the fourteenth Amendment.⁶² If care must be provided on an urgent basis, then the “emergency exception” may apply. In these situations, a health care provider generally will be shielded from liability based on lack of consent, because the provided care was too urgent to obtain proper consent. The limits of the emergency exception were examined in a 1920 case, *Moss v. Rishworth*. A doctor obtained consent for a tonsillectomy from a sibling. Although the surgery was indicated and no negligence was found with the care, the parents prevailed based on their claim of lack of informed consent.⁶³

The *Miller* court pointed out that the right for parents to consent is a fundamental right, but *not* an absolute one.⁶⁴ An extensive list of examples was presented in which the state was allowed to interfere with parental decision-making. Instances when the state can interfere with absolute parental rights include mandatory newborn screening, mandatory syphilis testing, mandatory immunizations, mandatory hearing and visual exams, mandatory attendance at school, prohibition on parents putting their children in the workforce, and court-ordered transfusions for children.

The Justices also noted that inherent in the right to consent is the corollary right to *not* consent.⁶⁵ The *Cruzan* decision largely empowered families and health care providers to decide to forgo life-sustaining care in cases of terminal illness or futility. Consistent with *Cruzan*, parents generally have the right to make these surrogate decisions for their own children.⁶⁶ Given this background of parents' right to determine the care and custody of their children, the court then examined the two other competing legal issues.

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Parents' Legal Duty to Provide Needed Care to Their Children

Part and parcel of a parent's right to make health care decisions for their children is the balancing duty of parents to ensure that their children are receiving necessary care. The *Miller* court cited the Texas Family Code,⁶⁷ and noted that failure to meet this duty may constitute a criminal act on the part of the parent.⁶⁸

State's Interest in Guarding the Well-Being of Minors

Acting as *parens patriae*, the state has this interest. It is clear that this interest can directly conflict with parents' rights and authority. As noted above, the court recited a partial list of instances when the state may interfere with parental decision-making. Parents' fundamental rights and authority may be restricted by the state, and, in the case of children, the state has considerable authority to oversee the care of children. After a detailed discussion of parents' rights, the right to refuse medical treatment, and the state's interest, the court articulates the issue as: Does a parent have a right to deny urgently needed life-sustaining medical treatment to their child, i.e., to decide, in effect, to let their child die?

While the Texas legislature has granted parents the right to withhold medical treatment if their child is terminal, this right does not exist because the child is otherwise disabled or impaired. In overturning the \$60 million verdict, the appellate court held that ". . . as a matter of first impression, a health care provider is not liable in tort for administering urgently needed life-sustaining medical treatment to newborn infant contrary to pre-birth instructions of parents not to do so."⁶⁹

The appellate court concluded that perhaps an exception should be made for extremely premature babies that are likely to be born in such critical condition that sustaining their life is not justified. Having stated this, the majority points out that such an exception, if desirable, would be a result of new legislation or a higher court.^{70,71}

Wrongful Birth and Wrongful Life: the Appellate Court's View

The court discusses the concepts of wrongful birth and wrongful life. Contrasts are drawn with other cases, and then these issues are dismissed.^{72,73} The court relies upon an earlier case and quotes: "The principal reason for this holding was the impossibility of rationally determining whether the child had actually been damaged by the birth because to do so would require weighing the relative benefits to her of an impaired life versus no life at all."⁷⁴

Appellate Court Dissent

The dissent in *HCA v. Miller* noted that no emergency existed. The physicians did not attempt to transfer care to another doctor who would have honored the parents' wishes. Also, the dissent notes that the hospital and physicians had 11 hours to either obtain a court order or discuss their thinking with the parents. The dissent points out that this was not an "emergency," and it was the appellant's

indecision and delay that led to the "emergency" nature of the care being provided. The dissent also noted that the most important issue is "the best interest of the child,"⁷⁵ and having a court hearing regarding the resuscitation would have allowed an impartial panel to make a decision.

Texas Supreme Court Holding in *Miller v. HCA*

Sidney Miller's parents appealed to the Texas Supreme Court. They claimed that the hospital was negligent and that a battery was committed because they did not consent to treatment. On September 30, 2003, after Sidney's 13th birthday, the Texas Supreme Court issued their final decision in *Miller v. HCA*.

The Supreme court of Texas agreed with the decision of the appellate court however the high court used a different analysis. The high court ruled that Sidney could not be fully evaluated until after she was born. Therefore, any decision made prior to birth was not fully informed. After the infant was born, the physician was faced with an "emergency" situation, and that emergency did not exist until such time that the infant was born. Since the physician did not have time to obtain consent after the birth or obtain a court order if the parents refused to consent, then the physician was justified in providing "emergency care" for the infant. The court ruled that the "emergency exception" to the informed consent doctrine applied, and therefore the physician did not need parental permission to resuscitate an extremely premature infant.

The court did reiterate that informed consent should be obtained, if this is possible. They stated, "Whenever possible, obtaining consent in writing to evaluate a premature infant at birth and to render any warranted medical treatment is the best course of action, but if such consent is not forthcoming, or is affirmatively denied, courts will decline to impose liability on a physician solely for providing life-sustaining treatment under emergent circumstances to a new-born infant without that consent."

The court further reasoned that ". . . the evidence further established that once the infant was born, the physician attending the birth was faced with emergent circumstances—i.e., the child might survive with treatment but would likely die if treatment was not provided before either parental consent or a court order overriding the withholding of such consent could be obtained. We hold that circumstances like these provide an exception to the general rule imposing liability on a physician for treating a child without consent."

Therefore the neonatologist's treatment of Sidney Miller was covered by the "emergency exception" to the informed consent doctrine. Thus, the Millers could not maintain their claim of battery. The Texas Supreme Court's findings have led to robust debate in the medical community. Theoretically, any neonatologist in the state of Texas could disregard predelivery requests by the parents concerning the forgoing of resuscitation. Since a physician cannot fully evaluate the situation until the infant is born, then parents' requests could be ignored.

An article from the *Houston Law Review*⁷⁶ argues that the Texas Supreme Court should have followed the dissent at

the appellate court level. This article suggests that parents should be empowered in these cases of birth of extremely premature infants.

Furthermore, the article suggests that the Texas Advanced Directives Act should be amended to include extremely premature infants. As noted above, at the appellate court level, there was a suggestion that the Texas legislature could rewrite the law to include extremely premature infants in the definition of “terminal.”

People v. Messenger

On February 8, 1994, Gregory and Traci Messenger had a similar experience to the Millers. When Traci Messenger went into labor at 25 weeks gestation, the parents considered the very high rate of severe complications for their son. The parents requested that their child *not* be intubated and ventilated. The physician assistant at the Lansing, Michigan, hospital disregarded the parents’ request and intubated the baby boy. At approximately one hour of age, Gregory Messenger, a dermatologist, removed his son from the ventilator and placed the baby in his mother’s arms. Without mechanical ventilation, the baby died. The attending physician wrote “homicide” on the death certificate. Dr. Messenger was subsequently charged with manslaughter.⁷⁷ Almost exactly one year later, Dr. Messenger was acquitted of manslaughter in the death of his newborn son.^{78,79}

The court cited authority for parents to withdraw care for their terminally ill children.⁸⁰ *In re Guardianship of Barry* addressed the issue of parents withdrawing care and letting their terminally ill children die. In this case, the child was a 10 month old who was terminally ill and “wholly lacking in cognitive brain functioning.” The parents, as guardian, petitioned the court to allow the withdrawal of life support. The trial court granted this request. The District Appellate Court noted that the trial court, in making their decision to allow the withdrawal of care, correctly applied the doctrine of “substituted judgment.”⁸¹

The Infant’s Protection Act and *Montalvo v. Borkovec*

Decision-making issues with regards to sick newborns remains difficult, contentious, and, as George Annas states, “as intractable today as it was 30 years ago, when it began to be publicly discussed.”⁸² Furthermore, while many seminal legal issues in this area are decided by the United States Supreme Court, the practice of medicine is generally regulated at the state level, and thus it is imperative that neonatologists stay abreast of state laws and regulations. In Missouri, for example, a closely watched statute may make it criminal to withdrawal support from an extremely premature infant.

Additionally, as the *Miller* and other cases demonstrate, important guidance comes not only from statutes, but also from case law, which, depending on the court, may or may not impact the practitioner directly. A recently decided Wisconsin case, *Montalvo v. Borkovec* (discussed below),

could be interpreted as requiring resuscitation of all extremely premature infants.

The Infant’s Protection Act was passed by the Missouri legislature in 1999, and indeed survived a gubernatorial veto. The law currently is not being enforced as a U.S. District Court ruled it unconstitutional, and a three-judge panel of the 8th U.S. Circuit Court of Appeals recently upheld this decision.⁸³ The law makes it a class A felony to cause “the death of a living infant with the purpose to cause said death by an overt act performed when the infant is partially born or born.” The term “living infant” refers to any infant who “has not attained the age of 30 days post birth.” On its face, extubating any infant in the first 30 days, even if while withdrawing care as felt to be in the best interests of the child as agreed upon by the parents and medical team, would violate the law and subject the physician to prosecution of a crime punishable by life in prison. Once again, the law is currently not enforced. Nevertheless it has been reported that the law did indeed have an impact on the care of some infants in Missouri.⁸⁴

While criminal penalties are not at stake, a recent Wisconsin case has potential implications for Wisconsin neonatologists. In *Montalvo v. Borkovec*,⁸⁵ a neonatologist who resuscitated a 23-week infant was sued by the parents for negligence for failing to sufficiently inform them of the risk of disability to the child following his birth via cesarean section. The Court of Appeals of Wisconsin, interpreting both the common law of Wisconsin and the United States Child Abuse Protection and Treatment Act (CAPTA) of 1984, 42 U.S.C. §5101 et seq., otherwise known as the Baby Doe Regulations, found that the infant’s parents had no right to withhold or withdraw treatment. The implication is that all infants need to be resuscitated, regardless of the wishes of the parents or providers. Further decisions or legislation are required to provide further guidance to neonatologists in this complex area.

WHEN PARENTS REQUEST CARE AND CLINICIANS REFUSE TO PROVIDE CARE

Hudson V. Texas Children’s Hospital

In 2005, the case of Terry Schiavo⁸⁶ received a tremendous amount of media attention. While the Schiavo case was extensively covered in the lay press, a case dealing with a dying infant in Houston received minimal media coverage. Sun Hudson⁸⁷ was born in Houston, Texas, on September 25, 2004, with thanotrophic dwarfism, a lethal form of congenital dwarfism. As such his prognosis was thought to be very poor. Like other infants with this ailment, he was ventilator-dependent and his lungs were unable to expand to accommodate his growing body. The medical team and ethics committee felt that withdrawal of support was in his best interests, but his mother disagreed and fought to keep Sun on the ventilator. The Advance Directives Act (chapter 166) of the Texas Health and Safety Code allows a physician to “refuse to honor” a parent’s treatment decision if

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several conditions are met, including agreement by the facilities' ethics committee and a ten-day delay during which the hospital must try to find a facility that will accept transfer of the patient. In this case the hospital contacted 40 other facilities, none of whom would accept transfer. Consequently, a Texas Probate Court judge allowed the hospital to extubate Sun against the wishes of his mother and he passed away shortly after he was extubated on March 15, 2005.

The Sun Hudson case is noteworthy in that a newborn's life-sustaining treatment was removed against the wishes of the legal guardian. As this case and the Schiavo case illustrate, it can be quite contentious when caregivers withdraw treatment without unanimous family consent. Caregivers should generally take all necessary steps to help reconcile the views of the family and the health care team. Legal actions may commence if family members feel that these decisions were made without their consent.

Smalling v. Gardner

On March 4, 2000, Stephanie Wortham Smalling gave birth at 23 weeks gestation to Skyler Kennedy Wortham-Krause. Apparently, no resuscitation was offered, and the parents were told that Skyler died within a few minutes of birth. In their court action, the parents maintained (among other allegations) that Skyler lived for at least two hours, and that she may have lived without comfort from her family. The family also maintained that proper care may not have been provided for their daughter. The parents also maintained that they were deprived of the right to nurture their child and that they (the parents) were denied the right to make informed decisions about the type of care Skyler might require or receive. The parents maintained that Skyler was denied ". . . proper attention, comfort, or custodial or palliative care."⁸⁸ Of note, the parents did not produce an expert witness to support their claims that the physicians' care deviated from that of a reasonably prudent physician. In an unreleased opinion, the Texas Appellate Court concluded that the physicians' failure to properly inform the family may have been wrong. However, the parents must show that the physicians did not act as reasonably prudent physicians.

In this case, the physicians elected to not resuscitate an infant born at 23 weeks gestation. The parents maintain that they were not given an opportunity to participate in the decision-making process. The court found the parents would need to present evidence that the care provided was substandard.

HANDICAPPED NEWBORNS

Baby Doe

There has been considerable interface between the legal system and those that care for "handicapped" newborns. The very definition of handicap, the allowable limitations on care provided for handicapped newborns, and the remedies available to babies, families, hospitals, and the state have been extensively debated and, in some cases, litigated.

During the early 1980s a series of court cases brought the issue of handicapped newborns to the mainstream.

Baby Doe only lived for six days. His brief life precipitated tremendous controversy⁸⁹ and plunged the neonatal community into a prolonged debate. Within three years of his death, the American Medical Association, the American Academy of Pediatrics, the Reagan Administration, and the United States Supreme Court would be involved in the debate. In 1983, when the U.S. Supreme Court denied certiorari,⁹⁰ the matter was far from resolved. More than 20 years after his death, the legacy of Baby Doe still affects the care provided to handicapped newborns all over the country.⁹¹

Infant Doe was born with Down syndrome on April 9, 1982 in Bloomington, Indiana. Despite the fact that children with Down's exhibit a wide range of developmental delay, Down syndrome is not considered to be a fatal syndrome. As is often the case with babies with Down syndrome, Infant Doe had an anomaly of the gastrointestinal tract. Although not the most common atresia associated with Down syndrome, Infant Doe had esophageal atresia.⁹² This anomaly prevents the external intake of fluid and nutrition. Without surgical correction, the baby would die. After the health care team spoke with the parents, the decision was made to withhold food and water until the baby died. Absent the diagnosis of Down syndrome, deferring surgical correction would not even have been considered as an option.

Baby Doe had a correctable surgical problem and an underlying syndrome that would lead to mental retardation. The baby was allowed to die because he had Down syndrome. Many observers felt that the decisions to defer surgery and to withhold nutrition were unreasonable. Many questioned the parents' rights to make such a decision for a child with a nonfatal syndrome such as Downs. A national controversy erupted following the baby's death. Amidst the controversy, advocates for the handicapped relied upon Section 504 of the Rehabilitation Act of 1973,⁹³ which prohibits discrimination based on handicap.

Subsequently, the Department of Health and Human Services issued guidelines that were designed to prevent handicapped newborns from being deprived of life-saving therapies solely because they were handicapped. At the request of President Reagan, a strong federal role was suggested in ensuring care be provided for handicapped newborns. Hospitals that received federal funds were required to post, "in a conspicuous place,"⁹⁴ a notice that a "hotline" was available for anyone to report a violation of the law to the Department of Health and Human Services. The American Academy of Pediatrics and other groups contested these guidelines. Ultimately, the guidelines were declared invalid.

Baby Jane Doe

On October 11, 1983, Baby Jane Doe was born with meningomyelocele, hydrocephalus, and other anomalies.⁹⁵ The baby's parents refused to give the hospital consent to repair the spinal defect and to drain the hydrocephalus.

The parents opted for nutritional support and antibiotics with the hope that the skin would grow over the defect and protect it. An attorney, who was unrelated to the family, filed for the appointment of a guardian *ad litem* for the baby. The federal government subsequently brought suit, under Section 504 of the 1973 Rehabilitation Act,⁹⁶ to discover whether or not the baby was the victim of discriminatory withholding of medical care based on her handicap.

The district court held that the federal government could compel access to the medical records in this case. This holding was overturned during the appellate process. The Second Circuit of the United States Court of Appeals affirmed⁹⁷ that the Department of Health and Human Services lacked the statutory authority to conduct the investigation and to access the medical records of Baby Jane Doe. This court also affirmed that the hospital was honoring the reasonable medical decision-making of the parents.

This case reached the U.S. Supreme Court in 1986. As noted above, in the original Baby Doe case, the United States Supreme Court denied certiorari. However, the High Court did ultimately consider the issue of the care of handicapped newborns.⁹⁸ In this case, the court not only reviewed the facts of the present case, Baby Jane Doe, but they also recapped the judicial history of Baby Doe.

The United States Supreme Court found (1) the parents had made a reasonable medical decision that could have been consistent with the best interests of the child, (2) withholding the surgical treatment was not discriminatory, and (3) the trial court had abused their discretion by allowing the proceedings to go forward.⁹⁹

The Supreme Court ruled that in order to violate Section 504, an "otherwise qualified" would have to be denied care "solely by reason of his handicap." The Supreme Court concluded that, absent parental consent, the withholding of treatment from a handicapped infant cannot violate Section 504.¹⁰⁰

ANENCEPHALY

Baby K

Anencephaly is a neural tube defect¹⁰¹ that leads to profound abnormality of brain development. The skull is incompletely formed and part of the brain is exposed to the amniotic fluid. In general, there is complete absence of the cerebral cortex and other vital neural structures. If the pregnancy is not terminated through spontaneous or surgical abortion, the newborns generally live for a few days or weeks. Absent heroic intervention, these babies generally die very soon after birth.¹⁰²

In October 13, 1992,¹⁰³ Baby K was born with anencephaly. The baby had respiratory distress. She was placed on mechanical ventilation so that her diagnosis could be confirmed, and so that the situation could be completely explained to her parents. Because of the extremely grim prognosis, the doctors recommended that the baby only receive warmth, fluids, and nutrition. The mother, based

on her firm religious beliefs, insisted that the baby receive mechanical ventilation if needed to sustain the baby's life. The hospital's efforts to transfer the baby to another facility were unsuccessful. After she no longer required intensive care, Baby K was transferred to a nursing home.

Baby K was readmitted to the original hospital on three occasions for respiratory distress. Each time, the mother insisted on intubation and mechanical ventilation. The hospital felt that providing this care was morally and ethically inappropriate, and they sought judicial intervention to allow them to stop providing what they perceived to be as, futile treatment. The hospital wanted clarification if they were obligated to provide emergency medical care for Baby K. Baby K's guardian and her father joined in the action, as they also felt that the baby should not be offered mechanical ventilation.¹⁰⁴ The mother prevailed. The case reached the 4th Circuit of the United States Court of Appeals in 1994.¹⁰⁵ This 4th Circuit affirmed the findings of the lower court, namely, that the hospital was obligated to provide the requested care under the Emergency Medical Treatment and Active Labor Act¹⁰⁶ (EMTALA). This act requires that participating hospitals provide emergency stabilizing treatment to any person with any emergency medical condition if that treatment is requested on their behalf. This act was known as "antidumping" legislation to prevent hospitals that received federal funds from withholding treatment or transferring unstable patients based on the patient's ability to pay.

The courts found that an anencephalic baby was handicapped and disabled,¹⁰⁷ and that the hospital could not circumvent the mother's request for life-saving intervention. The sole reason to withhold therapy would be the anencephaly, and this withholding would violate EMTALA as well as the Americans with Disabilities Act (ADA).¹⁰⁸

ETHICS

In neonatology, as in most medical specialties, there is considerable crossover between law and ethics. Those who take care of sick newborns regularly deal with concepts such as informed consent, autonomy, right to die, surrogate decision-making, beneficence, nonmaleficence, truth-telling, etc. On a daily basis, health care providers and families must face extremely sensitive issues while caring for the most fragile of patients. The overall trend has been toward parental autonomy as long as reasonable decisions are being made.

While a detailed review of perinatal/neonatal ethics is beyond the scope of this chapter, complex ethical issues are inherent in all of the court cases contained herein. The very essence of "personhood" or being "born alive" is a fundamental issue in many of the most challenging NICU cases. What are the limits on a parent's right to make health care decisions for their newborns? When is it acceptable to forgo resuscitation on an extremely premature baby?¹⁰⁹ What are the limits of viability? At what gestation, if any, should a physician (or judge) be able to "overrule" a parent's request?

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While some difficult questions have been addressed by the legislative and judicial branches, many more complex issues await resolution. In some cases, such as *Baby K*,¹¹⁰ physicians have been given the clear message that they cannot be solely guided by their own ethical principles. Yet in other cases, such as *Miller*, the parents' rights and ethical convictions were overruled. Given the available information, it appears that the Millers made a loving, informed, and heart-breaking decision regarding the care of their child. Because of legal uncertainties, the Millers' ethical convictions were discarded by the health care system and the judicial system.

One notable, guiding ethical principle that has emerged from the last 20 years of neonatal cases is the "best interest" standard.¹¹¹ In a case brought before the District of Columbia Court of Appeals, a neglected child's guardian determined that a "do not resuscitate" (DNR) order was in the best interest of that child. The court supported the guardian's decision and ruled that the "best interests" of the child standard, rather than "substituted judgment" standard, applied with respect to DNR determination.

For many years, the "substituted judgment" standard was used. In a situation where the patient is unable to communicate their own wishes, the "substituted judgment" principle compelled the guardian or decision-maker to determine, as best they could, the appropriate course of action based on what the incapacitated individual would have decided. Because a sick newborn has never been able to communicate their intentions, a guardian makes essentially all the health care decisions. This case clarified that the "best interest" standard was most appropriate. This test simply asks if the decisions being made are consistent with the child's best interest.

SUMMARY AND CONCLUSIONS

At the border of fetal existence and "personhood" is a largely undefined legal transition. The critically ill newborn often exists at this legal crossroads. As a fetus, *Roe v. Wade* and its progeny govern. After being born alive, the sick newborn can still be distinguished from other persons. There is a small, but growing, body of law that governs the "never aware," and the "never competent." In some instances, the courts have based their holding on the fact that extreme prematurity is not necessarily "terminal," and therefore withholding or withdrawing care is not an available option to the parents/guardians. Other courts have found that forgoing resuscitation may be acceptable medical practice.

On the one hand, various courts have said that the parents do not necessarily have the right to refuse resuscitation. On the other hand, Dr. Messenger removed his own son from the ventilator and was found innocent of manslaughter.

How does one reconcile the *Miller* case and the *Messenger* case? If an extremely premature baby is resuscitated against the parents' wishes and the baby is tremendously damaged as the result of that prematurity, then the parents cannot sustain a cause of action. However, if an extremely premature baby is resuscitated against the parents' wishes, and

the father removes the baby from the ventilator, no homicide has been committed. So what is the legal standing of a critically ill newborn? In one case, these babies can be cared for against the parents' wishes with no liability for the caregivers. In the other case, the infant can be removed from support by the parents against the caregivers' wishes, and there is no liability for the parent.

Further complicating the picture is the *Smalling* case. In this case the parents maintain that their 23-week gestation infant was allowed to die without their permission. They maintain that they were not adequately consulted in the decision-making process and that denying resuscitation to their infant may not have met the standard of care for a neonatologist. The court ruled that the Smalling family must support their claim with expert testimony. Attempts to reconcile the findings in *Miller* and *Smalling* raise various questions. Is resuscitation of a 23-week infant "standard of care"? Is there liability for a neonatologist that resuscitates a 23-week infant without parental permission? In the *Miller* case, the answer is "no." Is there liability for a neonatologist that does *not* resuscitate a 23-week infant even if the parents may have desired resuscitation? In the *Smalling* case, the answer is "no." Of note, these are both very recent cases and both cases were adjudicated in the state of Texas. It would appear that Texas neonatologists may be free to use their own discretion when deciding whether or not to resuscitate extremely premature infants. Resuscitation without permission leads to no liability (*Miller*). Foregoing resuscitation without permission leads to no liability (*Smalling*).

The *Baby K* case adds yet another dimension to the legal landscape. Given the extremely grim prognosis for anencephalic babies, the *Baby K* case was largely seen as a strong vindication of parents' right to determine the care of their children. The case also sent a clear message to doctors and other health care providers that their personal ethics will be subjugated to parental wishes, even if the parental request is perceived as extremely unreasonable. Providing ventilatory support to a child without a cerebral cortex was mandated by the court.

For thousands of years, medical care has been provided based on benefit to the patient.¹¹² In the case of *Baby K*, the court mandated that doctors provide what is largely viewed as futile and inappropriate care. In the *Miller* case, the court found that the parents could not recover when their daughter received care that the parents felt was futile and inappropriate. In the *Messenger* case, the court found that the father was not criminally liable for an unauthorized termination of care that he felt was futile and inappropriate. In the *Gardner* case, the parents could not maintain a cause of action unless they could demonstrate that refusing to resuscitate is not "standard of care." In *Montalvo*, the court implies that all premature infants must be resuscitated.

Given this body of apparently conflicting law, no court has fully clarified the underlying issue of the legal status of extremely sick and premature newborns. Thus far, courts have done little to provide needed direction for neonatologists, obstetricians, staff, hospitals, and parents

of sick newborns. Perhaps the state legislatures will intervene. Until a higher court or legislature deals definitively with these issues, the care, withholding of care, and withdrawal of care for critically ill newborns will continue to be surrounded by legal uncertainty.

Endnotes

1. *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W. 3d 758 (Tex. 2003) at 761.
2. <http://www.cnn.com/2005/LAW/03/18/schiavo.brain-damaged/>.
3. *Miller, supra*, at 772.
4. R.M. Turbow & J.M. Fanaroff, *Legal Issues in Neonatal-Perinatal Medicine in*, R.J. Martin, A.A. Fanaroff, & W.C. Walsh (eds.), *Neonatal-Perinatal Medicine* 8th ed., vol. 1, pp. 47–62 (Mosby, 2005).
5. Albert R. Jonsen, *Issues in Procreational Autonomy: Transition from Fetus to Infant: A Problem For Law and Ethics*, 37 *Hastings Law Journal* 697 (1986).
6. AL Code 1975 §22-9A-1 (2005).
7. I.C.A. §144.1 (2005).
8. AK ST §18.50.950 (2005).
9. 22 M.R.S.A. §1595 (2005).
10. 35 P.S. §450.105 (2005).
11. AL Code 1975 §26-22-2 (2005). This Alabama statute is from the Vital Statistics subsection of the Health, Mental Health, and Environmental Control.
12. 65 A.L.R. 3d 413 (1975) (proof of live birth in prosecution for killing newborn child).
13. *Greco v. United States*, 111 Nev. 405, 893 P. 2d 345 (1995). The court discussed the complexity of trying to decide if the child would be better off had he never been born. The court notes that they would have to weigh the harms of being handicapped against the “utter void of non-existence.” See also Marc Franklin & Robert Rabin, *Tort Law and Alternatives* (1996) at 258.
14. *Turpin v. Sortini*, 32 Cal. 3d 220, 643 P. 2d 954 (1982).
15. *Miller, supra* note 1, at 765.
16. The majority of states now allow a wrongful death cause of action for a fetal death. For cases and statutes on point in Nevada, Minnesota, Indiana, and Georgia see *White v. Yup*, 458 P. 2d 617, Nev. 527 (1969), 229 Minn at 370–71, 38 N.W. 2d at 841, *Bolin v. Wingert*, 764 N.E. 2d 201, Ind. (2002), and *Shirley v. Bacon*, 267 S.E. 2d 809.
17. *Farley v Sartin*, 466 S.E. 2d 522 W.Va. (1995).
18. Ca. Const. Art. 1, §7, see also *Justus v. Atchison* 19 Cal. 3d 564, 565 P. 2d 122 (1977).
19. *Dillon v Legg*, 68 Cal. 2d 728, 441 P. 2d 912, 69 Cal. Rptr. 72 (1968). The California Supreme Court discussed the foreseeability of emotional injury.
20. New Jersey Model Civil Jury Charge. Charge 5.15. Negligence—Emotional Distress from Witnessing Serious Injury to an Intimate Family Member. Accessed Jan.26, 2006, at <http://www.judiciary.state.nj.us/civil/civindx.htm>.
21. C.C.P. §377.34.
22. *Vo v. Superior Court in and for County of Maricopa*, 836 P. 2d 408 (1992).
23. At oral arguments in *Vo*, counsel informed the court that the fetus was 23 weeks gestation at the time of the death.
24. *Vo, supra*, at 206.
25. *Id.*
26. AZ ST §13–1103, subsection A.5.
27. A.L.R. 1975, *supra* note 12.
28. *Vo, supra* note 22.
29. AZ §13-1101, *supra* Note 26.
30. *Maricopa County*, Cause No. CR 97-09388, Thomas Dunevant, III, J.
31. *State v Cotton*, 5 P. 3d 918, Ariz. App. Div. 1 (2000).
32. Richard J. Martin, Michelle Walsh, & Avroy A. Fanaroff, *Neonatal-Perinatal Medicine: Diseases of the Fetus and Infant*, 8th ed. 1041 (Mosby, 2005).
33. Robert Creasy, Robert Resnik, & Jay Iams, *Maternal-Fetal Medicine. Principles and Practice*, 5th ed. (Saunders, 2004) at 220.
34. Thomas E. Wiswell & Steven Donn (eds.), *Update on Mechanical Ventilation and Exogenous Surfactant*, 28(3), *Clinics in Perinatology* (W.B. Saunders, 2001). The reader is referred to “Biology of Surfactant” by Alan Jobe & Machiko Ikegami on p. 655 of this journal, and also “Current Surfactant Use in Premature Infants” by Gautham K. Suresh & Roger F. Soll on p. 671.
35. Mark C. Mammel, *High Frequency Ventilation, in Assisted Ventilation of the Neonate* Jay P. Goldsmith & Edward H. Karotkin (eds.) 4th ed. 183 (W.B. Saunders, 2003).
36. David R. Gerstmann, Steven D. Minton, et al, *The Provo Multicenter Early High-Frequency Oscillatory Ventilation Trial: Improved Pulmonary and Clinical Outcome in Respiratory Distress Syndrome*, 98(6) *Pediatrics* 1044 (1996).
37. Steven M. Donn and Michael A. Becker, *Special Ventilatory Techniques and Modalities I: Patient-Triggered Ventilation, in Assisted Ventilation of the Neonate, id.* at 203–218.
38. S.R. Hintz, D.E. Kendrick, et al., *Changes in Neurodevelopmental Outcomes at 18 to 22 Months’ Corrected Age Among Infants of Less Than 25 Weeks’ Gestational Age Born in 1993–1999*. *Pediatrics* 1645–1651, 115(6) (2005).
39. Carl T. D’Angio, Robert A. Sinkin, et al, *Longitudinal, 15-Year Follow-Up of Children Born at Less than 29 Weeks’ Gestation after Introduction of Surfactant Therapy into a Region: Neurologic, Cognitive, and Educational Outcomes*, 110(6) *Pediatrics* 1094 (2002). This study presented data at age 7 years and 14 years. While there has continued to be refinement of NICU care since these children were born in the mid- 1980s, this study included babies born at 27 and 28 weeks gestation. It is worth noting that some larger infants also suffered a significant intracranial hemorrhage and/or now have significant neurologic deficits.
40. *Id.* at 1097.
41. Rita G. Harper, Khalil U. Rehman, et al, *Neonatal Outcome of Infants Born at 500 to 800 Grams from 1990 Through 1998 in a Tertiary Care Center*, 22(7) *Journal of Perinatology* 555, 559 (2002).
42. Maureen Hack and Avroy Fanaroff, *Outcomes of Extremely Immature Infants: A Perinatal Dilemma*, 329(22), *New England Journal of Medicine*, 1649 (1993).
43. D. Wilson-Costello, H. Friedman, et al., *Improved Survival Rates with Increased Neurodevelopmental Disability for Extremely Low Birth Weight Infants in the 1990s*, 115(4), *Pediatrics*, 997–1003, (2005).
44. J.L. Peabody and G.I. Martin, *From How Small Is Too Small to How Much Is Too Much: Ethical Issues at the Limits of Neonatal Viability*, 23(3), *Clinics in Perinatology* (Gary E. Freed & Joseph R. Hageman, eds.), 473–489, (1996). This article provides a detailed analysis of a multitude of ethical issues in newborn care. Readers are also referred to the endnotes of this article. Many of the landmark papers concerning neonatal outcomes are cited.
45. *Roe v. Wade*, 410 U.S. 113, 93 S.Ct. 705 (1973).
46. *Id.* at 159.
47. Jonsen, *supra* note 5. This treatise discusses the sanctity and quality of life issues, and addresses some of the “border” issues concerning fetuses and newborns.
48. *Roe, supra*. note 45. In this 1973 case, Justice Blackmun does note that viability was generally considered around 28 weeks and possibly as early as 24 weeks.

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49. *Akron v Akron Center for Reproductive Health*, 462 U.S. 416 (1983).
50. *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 112 S.Ct. 2791 (1992).
51. *Id.*
52. *Id.*
53. H. McDonald and the Committee on the Fetus and Newborn, *Perinatal Care at the Threshold of Viability*, 110(5) *Pediatrics* (Nov. 5, 2002). This article reviews important outcome statistics and suggests some guidelines for counseling of families facing the birth of an extremely premature child. J. A. Lemons, C.R. Bauer, W.Oh, et al. *Very Low Birth Weight Outcomes of the National Institute of Child Health And Human Development Neonatal Research Network, January 1995 through December 1996* 107(1) *Pediatrics* (2000).
54. *Id.*
55. *HCA, Inc. v. Miller ex rel. Miller*. 36 S.W. 3d. 18, 190 (2000).
56. *Id.*
57. *Id.*
58. This value represented the sum of \$29,400,000 for past and future medical expenses, \$13,500,000 in punitive damages, and \$17,503,066 in prejudgment interest.
59. *Health Care Law*, 55 *SMU L. Rev.* 1113, 1153 (2002).
60. Advanced Directives Act. V.T.C.A., Health & Safety Code §§166.002(13), 166.031, 166.035.
61. *HCA v. Miller*, *supra* note 55, at 195.
62. *Troxel v. Granville*, 530 U.S. 57, 120 S.Ct. 2054, 2060, 147 L.Ed. 2d 49 (2000). This case cites the fourteenth Amendment to the U.S. Constitution as the basis for this parental interest. The U.S. Supreme Court has described this liberty interest as a fundamental right. Justice O'Connor with the Chief Justice and two Justices concurring states that "custody, care, and nurture of child reside first with parents, whose primary function and freedom include preparing for obligations the state can neither supply or hinder."
63. *Moss v. Rishworth*, 222 S.W. 225 Tex. Com. App. 1920, (June 2, 1920).
64. *Prince v. Massachusetts*, 64 S.Ct. 438 U.S. 1944.
65. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 270, 110 S.Ct. 2841, 111 L.Ed. 2d 224 (1990).
66. V.T.C.A., Health & Safety Code §166.035.
67. Texas Family Code Ann. §151.003(a)(3).
68. Texas Penal §22.04.
69. *HCA v. Miller*, *supra* note 55, at 187.
70. *Id.* at 195.
71. John J. Paris & Frank Reardon, *Bad Cases Make Bad Law: HCA v. Miller Is Not a Guide for Resuscitation of Extremely Premature Newborns*, 21(8), *Journal of Perinatology*, 542 (2001). This journal article comprehensively discusses the case, and urges that decisions regarding resuscitation and care of extremely premature babies lie with the parents. Father John Paris has written extensively on the issues of neonatal ethics as well as many other topics in biomedical ethics.
72. *Nelson v. Krusen*, 678 S.W. 2d 918 (1984).
73. *Jacobs v. Theimer*, 519 S.W. 2d 846, 847 (1975).
74. *Nelson*, *supra* note 72, at 925. In *Nelson*, parents and minor son sued doctor and medical center alleging that doctor was negligent in assuring them that mother was not a carrier of neuro-muscular disease.
75. *HCA v. Miller*, *supra* note 55, at 197.
76. H.O. Rumbaugh, *Miller v. HCA, Inc.: Disempowering Parents from Making Medical Treatment Decisions for Severely Premature Babies*, 41, *Houston Law Review* 675 (2004).
77. *People v. Messenger*, No. 94-67694-FH, 30th Judicial Circuit Court for County of Ingham (Michigan), decided Feb. 2, 1995 (Judge Harrison's Court).
78. *Independent (London)* 39,40,42, (Nov.11, 2000) WL 26289589, Copyright 2000 Independent Newspapers (UK) Limited.
79. *Man acquitted in son's death*, N.Y. Times Abstracts 10, (Feb.4, 1995).
80. *In re Guardianship of Barry*, 445 So. 2d 365 Fla. App. 2 Dist, (1984). This case involved a terminally ill 10-month-old child who had essentially no cognitive function or chance of improvement. The parents, as guardians, petitioned to have life support removed. The request was granted.
81. *Id.* For a more detailed discussion of "substituted judgment" vs. "best interest", the reader is referred to the Ethics section of this chapter.
82. G.J. Annas, *Extremely Preterm Birth and Parental Authority to Refuse Treatment—The Case of Sidney Miller*, 351 *New Engl. J. Med.* 2118–2123 (1994).
83. J. Mannies, *8th Circuit Finds Missouri Abortion Law Unconstitutional* St. Louis Post-Dispatch, (Nov. 29, 2005).
84. F.I. Clark, *Treatment Decisions for Critically Ill Infants: The Abrogation of the Best Interests Standard* *Juv. Fam. Ct. J.* 11–22 (2004).
85. *Montalvo v Borkovec*, WI App. 147, 256 Wis. 2d 472, 647 N.W. 2d 413 (2002).
86. <http://www.washingtonpost.com/wp-dyn/articles/A15423-2005Mar31.html>.
87. *Hudson v Texas Children's Hospital*, 177 S.W. 3d 232.
88. *Smalling v. Gardner*, S.W. 3d No. 14-03-01079-CV, March 10, 2005 (unreleased opinion) at 2.
89. *Infant Doe v. Bloomington Hospital*, 104 S.Ct. 394.
90. *Infant Doe v. Bloomington Hospital*, 464 U.S. 961 (1983).
91. 45 C.F.R. §84.55, Code of Federal Regulations Part 84, Nondiscrimination on the Basis of Handicap; Sec. 84.55, Procedure relating to health care for handicapped infants (2002). These regulations encourage facilities that receive federal funds to establish Infant Review Committees.
92. G.W. Gross *Radiology in the Intensive Care Nursery*, in *Intensive Care of the Fetus and Neonate Alan, Spitzer* (ed.), 2d ed. 478–480 (Mosby, 2000). Duodenal or jejunal atresia are more commonly seen in association with Down syndrome. All of these atresias are, generally, surgically correctable. Surgical correction of esophageal atresia can be more problematic, but this surgery is routinely done at children's hospitals nationwide.
93. 29 U.S.C.A. §794.
94. 48 Fed. Reg. 9630. Notices were to be prominently posted in delivery wards, maternity wards, pediatric wards, and each nursery.
95. *United States v. University Hospital of the State University of New York at Stony Brook*, 575 F. Supp. 607, 610 (1983). Judicial history includes *Weber v. Stony Brook Hospital*, 95 A.D. 2d 587. See also *Weber v. Stony Brook Hospital*, 60 N.Y. 2d 208.
96. *Supra*, note 93.
97. *U.S. v. University Hosp., State University of New York*, 729 F. 2d 144 (1984). As noted, the 2d District also noted the abuse of discretion by the trial court.
98. *Bowen v. American Hospital Assn.*, 476 U.S. 610 (1986).
99. The Appellate Division of the Supreme Court of the State of New York noted the abuse of discretion by the trial court.
100. *Id.*
101. *Martin supra* note 32 at 901. The neural tube is a primitive embryological structure from which the central nervous system develops. Abnormalities in the neural tube lead to a variety of conditions including anencephaly.

102. *Id.* at 901.
103. *In the Matter of Baby K*, United States District Court, Civ A. 93-68-A, 4 Nat. Disability Law Rep. 219
104. *Id.* at 1026.
105. *In the Matter of Baby K*, United States Court of Appeals, 4th Circuit, 62 U.S.L.W. 2504 at 592.
106. 42 U.S.C. §1395dd.
107. 29 U.S.C.A. §794. See note 73 above. The baby lacked cognitive function, and was “disabled” and “handicapped” within the meaning of the Rehabilitation Act of 1973 §504.
108. 42 U.S.C.A. §§12102(2).
109. Ehrnle W Young & David K Stevenson, *Limiting Treatment for Extremely Premature, Low Birth-Weight Infants (500-750) Grams*, 145(11) American Journal of Diseases in Children 1223 (1990).
110. *Baby K*, *supra* note 103.
111. *In re K.I.*, 735 A. 2d 448 (1999). The medical guardian *ad litem* requested a “do not resuscitate” (DNR) order. Appellate court ruled that the “best interest” of the child was preferable to the “substituted judgment” standard.
112. Janna C Merrick, *Critically Ill Newborns and the Law*, 16 Journal of Legal Medicine 189 (1995).

