

*Preterm but Not Predetermined:
The Challenges, Repercussions, and Victories of Extremely Preterm
Birth*

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Abstract: Kelley Benham gave birth to her daughter only 23 weeks and 6 days into her pregnancy, barely on the cusp of viability. As a result of this extremely preterm birth, Kelley and Tom’s daughter was statistically unlikely to survive, especially without disability. While preterm birth is an issue facing much of the world, the United States has a disproportionate amount of preterm births, which drives up health care costs in Neonatal Intensive Care Units, as well as creates the potential for many children to be disabled. Through utilizing Kelley and Tom’s memoir, World Health Organization policies and public health solutions, scientific research papers, and scientific literature about preterm birth, this case study examines preterm birth in the context of its effect on development of the child, the efficacy of Neonatal Intensive Care Units and other systems set in place to assist preterm babies, laws on children and medicine, who should bear the responsibility of making decisions for the child, and navigating whether a chance at life outweighs all of the costs. Undergoing countless treatments and procedures, Kelley and Tom, with the help of the doctors, decided to continue with interventions, grappling with the question of whether the treatments were worth it. Throughout this painful and heart-wrenching journey, Kelley demonstrates resilience, strength, unrelenting love, and what it means to be a mother, even when all of the odds are against her.

“He reached in and felt the baby’s feet, just where I knew he would find them. A second doctor confirmed it. “We have to go now,” she said. We’d made it 23 weeks and six days.” – *Kelley Benham* (Benham 2012).

23 Weeks and 6 Days

Kelley started bleeding on a Sunday. She was 20 weeks into her pregnancy, just a few days after her ultrasound had shown a normal fetus growing inside of her (NPR staff 2016). She and her husband, Tom French, rushed to the emergency room while copious amounts of blood and vomit left her body. When they arrived and everyone, including Kelley, assumed the baby had died, medical personnel desperately searched for any sign of life. After a painfully long time, a tech found a heartbeat; however, in an ultrasound, they also found a blood clot near the baby’s head, meaning Kelley’s placenta was separating from her uterine wall. Eventually, the doctors stabilized Kelley, but with a warning: she must, somehow, not go into labor until 24 weeks. She had to get through another month of pregnancy for her baby to be viable—for her to be able to have a child (Benham 2012).

Survival Against the Odds

Scientists have developed different ideas of what viability means in terms of the baby's ability to survive. Currently, the Journal of Perinatology claims that "infants born at more than 25 weeks' gestation with a birth weight above 600g are mature enough to warrant initiation of intensive care, as the majority of these patients survive..." (Seri and Evans 2008). Providing care to less than mature infants could be medically futile, meaning the infant would not improve, despite the interventions (Seri and Evans 2008). In addition to gestational age and weight, Gattie et al. (2012) examined brain development as an indication of viability. They found that once a fetus is 24 weeks, the central nervous system has developed in the form of a neural tube, cells have migrated to their final places in the brain, the skin has formed and developed receptors, and automatic movements are able to be generated. At 24 weeks exactly, an infant's brain is able to respond to sensory stimuli, which represents the point at which the infant can react to the environment through connections between sensory organs (i.e., the skin, the eyes, the ears, the mouth, and the nose) and the brain (Gattie et al. 2012). Just before this period marking maturity of the brain, however, exists a period of gestation termed the "Gray Zone," where infants are born between 23 and 24 weeks with a birth weight of 500 to 599 g (Seri and Evans 2008). Because "the line between patient autonomy and medical futility is blurred," more factors, such as response to intensive care interventions and prenatal factors, must be weighed in order to determine how long to continue care (Seri and Evans 2008).

Statistically, even if a baby is successfully born during the period of viability, he or she is unlikely to survive, especially without disability. The probability of Kelley's baby dying in the Neonatal Intensive Care Unit (NICU), regardless of the procedures, was 50%; the probability of her dying or being severely disabled was 68%; the probability of her dying or being moderately disabled was 80%; and the probability of her living with relatively no disabilities was 20% (Benham 2012).

According to Joy Lawn, M.D., PhD, "Preterm births account for almost half of all newborn deaths worldwide and are now the second leading cause of death in children under 5, after pneumonia" (WHO 2012). Significantly, more than 1 in 10 babies born are considered pre-term, meaning they are born before 37 weeks of gestation, and this number is rising, mainly due to a lack of prenatal care (WHO 2012). While the cases that require the most care are those like Kelley's and Tom's baby, referred to as "extremely preterm," even babies born 2 weeks before full-term babies (39 weeks) have twice the mortality rate. In developed countries, most pre-term babies are able to get the necessary care, but in less developed countries, only 10 percent of extremely preterm babies survive (WHO 2012).

Kelley and Tom

Kelley and Tom met in high school, although they didn't start dating until many years later. In the meantime, Tom married and divorced, and they both established themselves as well-acclaimed journalists. On paper, they did not fit together: Kelley was strong and unfiltered, handy around the house, loved animals and the outdoors, and was adventurous; but Tom, on the other hand, was none of these things. Rather, he was passionate, a great father, and fearful of new things. Despite these differences, their chemistry was undeniable. Kelley says of Tom, "He was interested in the world, its history, its richness, its forces and counterforces. All its crazy beauty became magnified and reflected in him, and when I was around him, it rained on me" (French and French 2016). After a whirlwind of dating in secret, officially dating, breaking up, getting back together, and then eventually getting married, they began the rest of their life together. Desperately wanting a child, Kelley and Tom tried again and again to get pregnant. After four-and-a-half years of trying

to conceive naturally, \$40,000, and two in vitro fertilizations, they finally opted for an egg donor (French and French 2016).

As Kelley details in her newspaper article, she made it to week 23, day 6 of her pregnancy—just short of the 24 weeks of confirmed viability. Before that, she had gone into labor several times, so had to check in and out of the hospital on several occasions. Each time, doctors tried to stall her labor by giving her drugs and elevating her feet. During this time, Kelley and Tom met with nurses, doctors, and neonatal counselors who provided information and advice. If they decided to have the baby, they could still reevaluate afterward, while she was in the NICU, about whether they wanted to continue the interventions to keep her alive. In essence, there was a critical period while the baby was on a ventilator where the parents could see how she progressed and determine whether they wanted to withdraw life support. The decision was not urgent; they could wait to see how fragile and weak the baby was, and then decide their course of action. Because Kelley and Tom had poured so much time, energy, and money into having this baby, not to mention their love, their hopes, and their dreams, they knew this child was their only shot to have a baby. If their baby did not live, they would not have another chance to be parents together. Hoping that Kelley's labor could be stalled until 24 weeks, Kelley and Tom decided to wait to make the huge and life changing decision of whether or not to provide care for their baby (Benham 2012).

Preterm Birth

More Common than we Think

According to the World Health Organization (WHO), in 2012, around 12% of babies are born prematurely in the world's poorest countries, versus 9% in more well-off countries. Consequently, 60% of all the world's preterm births occur in South Asia and sub-Saharan Africa. The United States, however, also ranks far above average in terms of number of preterm births, meaning this problem is not just plaguing lower-income countries (WHO 2012).

While no single cause has been discovered, the World Health Organization (WHO) has identified patterns linked to country income that often lead to preterm birth (WHO 2012). In high-income, developed countries, preterm births are connected to the mother's age, higher usage of fertility drugs, and multiple pregnancies. Often, medically unnecessary inductions of labor, as well as Caesarian sections prior to reaching full-term can cause an increase in preterm births. In low-income, developing countries, preterm births are usually caused by infections, malaria, HIV, and high teen pregnancy rates. Other risk factors independent of one's residence include prior history of preterm birth, being underweight, obesity, having diabetes or hypertension, smoking, infection, maternal age, genetics, multifetal pregnancy (i.e., having twins, triples, etc.), and pregnancies too close together (WHO 2012). Additionally, adverse life events, such as "chronic and catastrophic stress exposure during pregnancy" (examples include homelessness, a natural disaster, or trauma) can have huge repercussions for the baby (Behrman and Butler 2007). Maternal anxiety, especially that stemming from the actual pregnancy, may also contribute to preterm birth (Behrman and Butler 2007). Overall, research points to the mother as the main determiner of a child's outcomes in terms of preterm birth; in contrast, there is a scarcity of research directly linking men to preterm birth (Daniels 2006). Despite these findings, the causes of preterm births are still often inexplicable.

Adding to the list of harmful risk factors, in vitro fertilization itself has been shown to increase the likelihood of preterm birth. In fact, researchers have found that in vitro fertilizations create poorer obstetric outcomes, specifically raising the odds of a baby being born with low birth

rate and/or prematurely (Sazonova et al. 2011). Kelley and Tom knew of these risks and were willing to take a chance in order to have a child (Benham 2012).

Week 23

On day 6 of week 23 of Kelley's pregnancy, Kelley started to experience sharp, cramping pain, "as if there were feet coming out of [her]" (French and French 2016, 88). Suddenly, without any more time to contemplate the complex decisions ahead of her and Tom, Kelley went into labor. She was rushed to the operating room for a cesarean section, and her baby was born. Immediately after birth, Kelley and Tom's baby had underdeveloped lungs, weak muscles, soft bones, newly formed fingernails and fingerprints, and measured to be a miniscule 570 grams (1 pound and 4 ounces) and 11.4 inches long. But she had a strong heart rate of 170 beats per minute, which boded well. The baby was soon placed in a "plastic box," an incubator to keep her warm, where the nurses threaded tubes down her mouth. Through these tubes they pumped first artificial lung surfactant in her lungs to keep them from collapsing, and then air, in and out, to keep them inflating and deflating like normal lungs. After her incubator was prepared, Kelley and Tom's baby was wheeled to the NICU, where she would continue to have machines and tubes take the place of her underdeveloped organs (French and French 2016). Seeing the baby in this state led Kelley to wonder if the doctors would continue to intervene on the baby's behalf until she and Tom said otherwise, or if the doctors would eventually recommend taking the baby off life support if she was not progressing (French and French 2016).

Once Kelley began labor, still months before her due date, neither she nor Tom knew the right course of action once their baby was born. Barely on the cusp of viability, the odds were not in Kelley and Tom's baby's favor; however, Kelley and Tom were unsure whether they should attempt to beat the odds. After all, the doctors are the experts—they know the risks, the data, and the procedures. But if the baby survives all of the interventions, the parents, not the doctors, then take her home. Although they consulted doctors, nurses, and other medical personnel, Kelley and Tom still felt unprepared to make a decision of this magnitude: the decision of whether they should let the NICU doctors intervene to try to save their baby. But is it even the parents' decision in the first place, or should it be the experts' decision? Generally, whose responsibility should it be to decide whether a baby is worth saving? The experts or the parents? And at one point in the intervention process should a decision be made?

The "Miracle of Birth" in the NICU

The Neonatal Intensive Care Unit aims to keep babies alive and stable after birth, regardless of the potential outcomes. If a baby becomes stable, then the doctors and parents must have an informed discussion about whether continuing treatment will pay off in the long run. Initially, though, for Kelley, "there was only a desperate struggle to maintain" the baby's life (Benham 2012). Throughout the first few days of Kelley's baby's life, however, pessimistic thoughts nagged Kelley. She questioned the "miracle of birth," thinking, "Ask me in a year if it's a miracle" (French and French 2016, 117). Once a baby leaves the NICU, if he or she even survives infancy, how does premature birth affect his or her development? Kelley and Tom grappled with the possibility that their baby might grow up with health problems that many children do not face.

Because preterm babies do not have fully developed skin, every touch of every person, needle, or piece of equipment can more easily activate pain receptors. Eventually, a child constantly exposed to pain, which often characterizes a child's time in the NICU, can develop hyperalgesia, where "the child experiences the same stimulation as being more and more painful

each time. Eventually the sensitive child's nervous system can register just a touch as pain" (Jepsen 2006, 56). Jepsen (2006) also states that as a result of these prolonged stress experiences in the NICU, preterm children become desensitized to pain and often develop high pain thresholds. Moreover, due to underdeveloped brains and nervous systems, preterm children are generally more sensitive to stress than full-term children; this chronic stress can cause both physiological problems in the child, as well as neuroanatomy changes, impacting the child's cognitive abilities. Similarly, the procedures and stress the child undergoes in the NICU can be considered long-term trauma, which ultimately can make the child more withdrawn, more dependent on his or her parents, triggered by other exposures to trauma, and more. Essentially, stress and trauma experienced in the NICU can cause both mental and physical dysfunction. While preterm birth negatively affects many aspects of development, protective factors do exist that act as buffers to an infant's risk of long-term health complications. Research has shown that females, more emotionally mature children, and children with more secure family and friend relationships are less likely to develop as severe developmental issues (Jepsen 2006).

To compound the difficulties many preterm children face, often their extremely early birth can impact the mother-infant relationship. Not only are the mother and child separated for a longer period than if the baby had been born at full term (Jepsen 2006), because the preterm child is less able to respond to social stimuli as a full-term baby, they are not able to cognitively organize gazes, affect, and motor stimuli—all qualities that normally shape the reciprocal relationship of the mother and infant. This lack of mother-child synchrony can then alter the mother's parenting style, as well as the coordination between the mother's and child's actions that normally characterizes development (Hack, Murray and Nosarti 2010).

According to Hack, Murray and Nosarti (2010), the three most common behavioral problems plaguing school-age children born preterm are attention and hyperactivity problems, emotional difficulties, and socialization issues. Neurologically, many preterm babies have shown abnormalities in brain structures in Magnetic Resonance Imaging (MRI) scans, likely due to their shifted brain development. Studies have shown that children with preterm births have higher rates of Attention-Deficit Hyperactivity Disorder (ADHD); are more likely to have depression and/or suicidality; have difficulty initiating social interaction; are more likely to have neuromotor delays, which contribute to socialization problems; and have higher rates of autism development. On a long-term scale, these behavioral outcomes can persist over time into adolescence, often manifesting in socialization difficulties, lower self-esteem, issues with depression, and anxiety problems. Regardless of the repercussions these preterm children face, the environment in which they grow up, including socioeconomic status, environmental stress, and parental education levels, can shape their outcomes for better or for worse (Hack, Murray and Nosarti 2010).

In order to paint a holistic picture of a child's future quality of life, the likelihood of disability must be evaluated. In a study done for the *New England Journal of Medicine*, researchers investigated the associations between children born at 25 weeks or earlier and the presence of neurologic and developmental disabilities when they were six years old (Marlow et al. 2005). First, the researchers evaluated the children's cognitive functions at 30 months old to establish a baseline. Next, to complete their longitudinal study, the researchers evaluated the same children again at 6 years old through a neuropsychological assessment, and then classified them into either severe, moderate, or mild groups of disability. Ultimately, the researchers found that cognitive and neurologic impairment was highly prevalent in extremely preterm children: 41% of children had cognitive impairments as compared to their classmates, 22% had severe disability, 24% had moderate disability, and 34% had mild disability, and 12% of children had cerebral palsy.

Additionally, the 86% of children with severe disability at 30 months still had moderate-to-severe disability at 6 years (Marlow et al. 2005). Because preterm children may sustain many of these potential disabilities throughout their lives, many families would also likely face both emotional and economic costs associated with a child with a disability (Jepsen 2006).

Knowing that their baby could face a future with some disabilities, Kelley and Tom grappled with the question of whether the prospect of having a life-altering disability is cause enough for halting interventions on a baby (Benham 2012). Usually, this conversation centers around abortions, but choosing to end a fetus's life and choosing to end an extremely preterm child's life have direct parallels. Martha Saxton of the World Institute on Disability argued in 1998 that medical professionals and public health officials encourage selective abortion if the fetus has been diagnosed with a disability. A disabled person herself, Saxton states, "We've come to realize that the stereotyped notions of the 'tragedy' and 'suffering' of 'the disabled' result from the isolation of disabled people in society. Disabled people with no connections to others with disabilities in their communities are, indeed, afflicted with the social role assignment of a tragic, burdensome existence" (Saxton 1998). She goes on to say that once someone with a disability acclimates and adapts to living a functional life, the stigma itself of having a disability becomes the true disability (Saxton 1998). While many might think that ending a fetus's life due to a disability would, in fact, save them from a lifetime of suffering, clearly there are groups whose views come into contention.

Neonatal Intensive Care Units—Modern Miracle or Medical Nemesis?

Neonatal Intensive Care Units, or NICUs, have proven to decrease infant mortality rates, especially that of critically ill babies. Post-birth, infants are mostly admitted to the NICU if they are premature, but also if they are full-term with acute illnesses or if they have congenital anomalies (e.g. Down syndrome or spina bifida) (Lantos and Meadow 2006).

Since the 1960s, NICUs have evolved through advancements in medicine. Innovations started with medical ventilation, which provided pressure-supported breathing for babies with respiratory distress, and moved to intubation, the process of placing a tube in the trachea in order to ventilate the lungs. Next came Total Parenteral Nutrition (TPN), a process that gives a patient full nutrition intravenously. Throughout the 1970s and 1980s, NICU technology was constantly improving, which directly improved outcomes for infants. New procedures included the treatment of respiratory failure, especially with the introduction of technologies that prevent lung collapse (i.e., lung surfactant), promote more natural ventilation patterns and increased blood oxidation, and promote blood vessel opening (Lantos and Meadow 2006).

The modern NICU was born from these early innovations, which shaped and altered the care of infants. However, Lantos and Meadow (2006) pose the question of whether the NICU is a "modern miracle or a medical nemesis" (5). As Kelley states, babies in the NICU are "suspended between what is medically possible and what is morally right" (Benham 2012).

Economically, one must consider whether the outcome of the NICU, for the patients, is worth the cost. For preterm babies, such as Kelley and Tom's baby, the average total cost per admission to the NICU is around \$90,000. Not only can this cost be a huge individual burden if parents do not have insurance, but if the insurance does cover these thousands of dollars, it can be a huge societal load as well. Overall, in 2004, the cost of NICUs in the United States, including medical follow-up and social costs of disability for patients, was around \$25-\$40 billion. 250,000 babies enter the NICU each year, which is about 0.1% of the population of the United States; however, the cost of NICUs makes up around 1% of the total national health expenditure. Thus,

we spend 1% of national health care expenditures on 0.1% of the population. In response to the NICU costs in the context of the national healthcare budget, researchers have investigated whether these costs could be lowered. Some studies have highlighted the fact that weight is inversely proportional to cost: lower birth weight babies cost more for the NICU to treat, and as birth weight rises, costs go down (Lantos and Marlow 2006). Not to mention the fact that the rate of low birth weight in African American babies has been shown to outnumber that of low birth weight in Caucasian babies by a factor of three (Kleinman and Kessel 1987). While these statistics point toward using treatment for babies who are farther along in development, denying lower birth weight babies treatment not only further increases the racial disparity of NICU deaths, but it also poses many important and difficult ethical issues in determining a baby's viability (Lantos and Marlow 2006).

But how does one quantify the cost of a child's life? If it means saving a child, are these expenditures worth it?

An Alien is Born

As soon as Kelley and Tom's baby was born, their baby was rushed to the NICU. Kelley, unable to move due to the procedure, sent Tom in pursuit of their daughter. The baby's skin papery thin, her veins bulging, Tom reached into her incubator (French and French 2016).

She immediately grabbed on to his pinkie finger. Instantly, he fell in love: "I was swept away. I saw her will, her beauty, all the possibilities waiting inside of her. She was a work in progress, yes. So was I" (French and French 2016, 99).

A while later, Kelley was able to see her baby, getting to see all of the tubes, the bruises on her body, her heart barely beating: "She was alien and familiar. She was terrifying and beautiful. She was complete and interrupted" (French and French 2016, 102). Again, when Kelley reached in to touch the baby, the baby grabbed on (French and French 2016).

Decisions

A Name

"The day she'd been born, we could have let her die, and no one would have judged us. Now it would be much harder to take her off life support. Our moral obligation had grown heavier" (French and French 2016, 145).

At the beginning, Kelley and Tom did not think their baby was going to survive past the first day. They decided to see what would happen in the few days after she was born, to see if she even had a fighting chance. After a few days, their baby was making strides – she had shown strength and resilience by simply staying alive, albeit tenuously. In response to this glimpse of hope, and because "French, Baby Girl" would not suffice as a name forever, they decided on a name: Juniper. Now that their baby had a name, however, it was hard to imagine letting her go, especially because she had been responding well to treatments. Tom and Kelley began to exist in a state of euphoria, imagining scenarios where Juniper would be okay. They could bring her home and raise their daughter like a normal family. She had started to become an even more tangible part of their lives (French and French 2016).

Juniper was born at All Children's Hospital in St. Petersburg, Florida. If she had been born a week earlier (i.e., lower gestational age and birth weight), All Children's would not have even

brought Juniper to the NICU, but rather would have declined to resuscitate because she would not have been viable. Even at the gestational age Juniper was born, other hospitals would not have tried to save her—either they would not have the resources equipped to deal with such premature babies, or they would have believed interventions were futile. And finally, if Kelley and Tom had not lived in the United States, resuscitation would not even had been possible or allowed (French and French 2016).

Once Juniper was born, the neonatologist at All Children’s told Kelley that “the team was doing everything they could. She didn’t tell me, until much later, that after working with thousands of babies over four decades, she was not sure this one would make it” (French and French 2016, 98).

The fact that All Children’s was one of only a small pool of hospitals that would even admit Kelley and Juniper in the first place begs the question of who should get to decide whether to resuscitate the baby after birth. If doctors believe that a baby is worth saving, should they or should they not be allowed input? And should the parents make the ultimate decision on whether or not to continue treatment for the baby? And what factors should drive this decision?

Child Abuse and Treatment Act

Alongside many of the NICU innovations in the late twentieth century, the United States government began to enact drastic measures to protect children and babies. In 1974, the U.S. Department of Health and Human Services created the Child Abuse and Treatment Act (CAPTA), a law that provides federal support for child protection agencies. In the 1980s, CAPTA was amended, specifying “three criteria for situations in which it would be permissible for doctors and parents to withhold or withdraw life-sustaining therapy” (Lantos and Meadow 2006, 73):

1. The infant is chronically and irreversibly comatose.
2. The provision of such treatment would—
 - a. merely prolong dying;
 - b. not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or;
 - c. otherwise be futile in terms of the survival of the infant.
3. The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane (Child Abuse and Treatment Act 2016, 37).

This amendment introduced the issues of neonatology to the legal world, and thus providing guidelines for doctors and parents to make decisions.

Doctors or Parents? Doctors and Parents?

Dominic Wilson, a neonatologist and ethicist, believes that the decision of whether or not to resuscitate should be based on prognosis, rather than gestational age. In other words, doctors should inform the parents about the stability and outlook of the baby, rather than just a number corresponding to an age. Similarly, both doctors and parents need to take into account whether the decision would “cause harm” to the child, which “involves a significant set-back to the child’s interests, which can be predicted with a reasonable degree of probability” (Gillam et al. 2017, 106). For example, is not intervening and just making the baby as comfortable in the hospital as possible until he/she passes more or less harmful than an intensive care intervention? Parents and doctors

must weigh short term versus long-term benefits—the baby’s chance at a pain-free first and last few days, or the baby’s chance at a longer life, but perhaps with disability. Furthermore, parents can make an initial decision to intervene knowing that they can always decide to withhold it after a time and not continue prolonging the baby’s life; however, this delay of the inevitable decision can cause stress to the baby. If the parents ultimately decide to stop intensive care, they have caused the baby unnecessary stress and trauma, and have perhaps forged a bond with the baby that then is taken away with the ventilator (Gillam et al. 2017).

According to Lynn Gillam, a clinical ethicist, hospitals should abide by the Zone of Parental Discretion, which states that “parents have a strong ethical (and legal) claim to be the decision-makers for their child, such that their decisions should not be over-ridden by others, unless they will cause harm to the child” (Gillam et al. 2017, 108). Therefore, clinicians must first consider the parents’ wishes before immediately treating a preterm patient. Additionally, clinicians should give medical background to the parents, who are often not medical experts, so that they can have a full understanding of their baby’s medical situation. Vicki Xafis, a clinical ethicist, states that “parents are acknowledged, ethically and legally, as having parental authority to make medical decisions for their children even if they are not *optimal* and even if clinicians *are not always in full agreement*. In practice, parents are not always included in decisions about their child, perhaps due to time constraints at the time decisions are made” (Gillam et al. 2017, 110). In response, Xafis advocates that normally, doctors and parents should use the Best Interests Principle, which state that both parties must consider the benefits and harms of the decision, or the Harm Principle, where parental authority is absolute unless parental decisions will harm the baby. In the case of an extremely premature baby, however, where a prognosis cannot be reliably predicted and the baby is on the borderline of viability, Xafis argues that doctors should not try to save the baby against the wishes of the parents because their actions cannot reasonably be justified, and ultimately, the parents and the child must live with that decision. Especially at the borderline of viability, one cannot claim that saving the baby is in the best interest of the child, as he/she could grow up with life-altering disabilities (Gillam et al. 2017).

The Laws Inside

In response to the confusion surrounding who is the rightful decision-maker, hospitals have adopted laws and procedures in order to set clear guidelines for treatment. For example, all hospitals in the United States have in place “informed consent” laws, which require medical staff to explain the purpose, details, and potential risks of a procedure. While informed consent laws do give illusory power to the parents of children in the NICU, they have shown to often provide the contrary (Mesman 2008). Studies have shown that these “informed consent” laws in fact give doctors the go-ahead to make the executive decisions for the patient because they have technically obtained consent from the parents (Mesman 2008). Luckily, Kelley and Tom did not experience this abuse of power, but other parents of preterm babies must figure out how to navigate these laws (Benham 2012). Furthermore, in NICUs, parents are frequently faced with the option of asking the doctors to issue Do-Not-Resuscitate (DNR) codes. Especially for parents of a preterm infant, DNR codes can be used to give power to the parents’ decision. Even if the parents and doctors come to this decision to not resuscitate together, the parents have the final say concerning to resuscitate their child. This system effectively allows the parents to decide when they want to stop subjecting their preterm baby to treatments and procedures. To compound the already complicated issue, however, some hospitals will not issue many DNR codes, meaning that only when a child is not

considered viable does treatment cease, giving the doctors absolute power under the law (Mesman 2008).

While these laws aim to protect both patients and doctors, they often complicate decisions by making one party an absolute decision-maker, depending on the specific hospital's preferences. Consequentially, NICUs have procedures and guidelines set in place to specifically treat their patients. For instance, the American Heart Association and the American Academy of Pediatrics have created the Neonatal Resuscitation Program (NRP), a program now central to the NICU. This program, in which a nurse can get certified, involves a set of protocols and algorithms that act as the industry standard for neonatal resuscitation. It acts as the equivalent of CPR guidelines for newborns and gives doctors and nurses specific guidelines to follow during treatment. (American Academy of Pediatrics 2017) (see Appendix A for more information).

Fortunately, the neonatologists and surgeons at All Children's were willing to work with Kelley and Tom. They put aside their own beliefs about whether or not to resuscitate and acted on Kelley's and Tom's wishes. At one point, Juniper's surgeon, Dr. Shakeel, approached Kelley, stating that "Babies are very, very resilient... Sometimes when the surgeons think the cause is lost, the babies put themselves back together. Sometimes babies like Juniper, with holes in their guts, never even return to the operating room" (French and French 2016, 195-6). Dr. Shakeel operated under the assumption that "where there's life... there's hope" (French and French 2016, 195-6).

Overall, according to Lantos and Meadow (2006), doctors and parents should share deniability, meaning that no one person is fully responsible for the decision, yet everyone had a voice.

Rising Tensions

Morals of the NICU

Morally, arguments have been made against the NICU. First, many medical personnel in the field of neonatology, as well as in other fields, have argued for preventative care, such as prenatal interventions, over NICU care; however, research has shown that preventative care can only go so far and does not get rid of the need for a NICU. Second, parents and doctors alike often believe that neonatology causes more harm than good in survivors of the NICU in the form of prolonged disabilities, as discussed earlier. Finally, NICUs have spurred the debate surrounding "quality of life," which compares the infants' levels of suffering and the preservation of life (Lantos and Meadow 2006).

Despite ongoing debates over the true effectiveness of NICUs, Lantos and Meadow (2006) cite Dr. Stahlman, who argues that there are, in fact, undeniable benefits of neonatology:

First, she demonstrated that there had been significant improvements in birthweight-specific survival rates. Second, she showed that many of the survivors who accounted for these improvements were neurologically intact. Finally, she argued that overall rates of 'non-intact' survival had not changed; instead, there was a shift in the subpopulations of babies with different outcomes—that babies who might have survived with deficits before the introduction of neonatal intensive care were now surviving intact but that some babies who otherwise would have died were now surviving with neurological problems... she saw [neonatal intensive care] as creating choices and responsibilities in situations where heretofore there had only been fate (38).

While the technology and skills developed by early neonatologists represented unprecedented innovation, they found themselves questioning whether the treatments would be fully effective. In other words, they could save lives, but not cure the diseases that often plague premature babies. Additionally, every baby is different, and it is difficult to tell which premature babies will react well to treatment in the NICU, and which babies will not. The chances of a baby who is born less than 750 grams reacting well versus dying in the NICU are about 50-50. Ethically, doctors must give all babies an equal shot at life because no one can tell how they will fare during interventions. As they develop, though, babies tend to display trends in improving or declining health, known as “declaring themselves” (Lantos and Meadow 2006, 92). For the sicker babies, this means that they will die, and for the healthier babies, this means that they will begin to improve over the first few days. This declaration can aid in a parent’s decision to pursue or not pursue treatment (Lantos and Meadow 2006).

Kelley and Tom were just waiting for Juniper to declare herself.

Ups and Downs

Soon after Kelley and Tom named Juniper, she began to experience complications. First, she developed necrotizing enterocolitis, characterized by a ruptured intestine. Immediately X-rayed and rushed into surgery, where surgeons “inserted a drain, like a soft drinking straw, to wick away the gunk in her belly” (French and French 2016, 140). On her sixth day, after this surgery to drain her abdomen, Juniper was screened for brain bleeding. Miraculously, the ultrasound showed no blood out of place (French and French 2016). Once Juniper’s brain was cleared, Kelley said that they:

Cleared a threshold. I wish I had recognized it then, because I was still spinning, grasping for any foothold on our future. But at that moment, while she still faced death or an array of handicaps beyond our control, the test suggested her brain could be okay. She might someday laugh, sing, and call me mom (French and French 2016, 145).

At this point, Tom began reading Juniper the first book of the *Harry Potter* series. Tom reasoned, “I want her to know she is not alone” (French and French 2016, 141). Kelley calls it “an act of faith... choosing the first book in a series that totaled more than four thousand pages. I knew he intended to read the entire thing... I knew this might be his only chance” (French and French 2016, 141).

While the lack of brain bleeding was one victory, Juniper was not improving. The ventilator to which she had been hooked since she was born had strained her lungs, so the doctors placed her on a gentler oscillating machine, vibrating her body and reminding Kelley of Juniper’s “sheer fragility” (French and French 2016, 142). Nonetheless, after a week of living in the NICU, Juniper began to perceive her surroundings, represented by changes in the oxygen saturation of her blood. For example, “when she was bothered by something—a loud voice or a tense conversation—the oxygen level in her blood would drop, triggering [the monitor’s] alarm” (French and French 2016, 144). Trying desperately to connect with her daughter, Kelley stuck a photo of herself and Tom to Juniper’s incubator, bought a soft blanket, and uploaded womb sounds onto an iPod. Another week passed. (French and French 2016).

Soon, when it was time for the incubators to be cleaned, Kelley got to hold Juniper for the first time. With her baby pressed up against her chest and her heart, Kelley felt complete again.

And Juniper began to breathe easier. As soon as this happy moment came, though, it left in a flash, and Juniper faced a whole new set of problems. Her umbilical lines were failing, so the doctors had to insert a central line, a tube in the arm or chest that brings nutrients, medicines, and fluids into the body. However, central lines in preterm babies often increase the likelihood of infection. The central line fell out of its proper place and harmfully pumped fluids into her chest cavity (French and French 2016).

Meanwhile, tensions between Kelley and Tom were growing. Their grief and sorrow was not bringing them together, but rather was alienating them from each other. Not only did Kelley mourn for her baby, but Tom was tired of always holding her up. They eventually resolved their differences, but Kelley often stayed behind to pump breastmilk when Tom went to the hospital to check on Juniper. She felt alone, but also didn't want to face the truth that the NICU held. She did not want to face the fact that she may not be able to bring her baby home (French and French 2016).

Time passed, and Juniper experienced more perforations in her stomach, more scares with blood pressure. One night, the doctor called Kelley and Tom and reported that they could not maintain Juniper's blood pressure or breathing or urination, meaning she likely had a huge infection. The NICU staff had her oxygen at 100% in order to stabilize her, which could blind her long-term. To make things worse, Juniper's blood was too acidic, so the doctors gave her system a buffer, but that also had burst through her IV and flooded into her hand. Over and over again, Juniper faced these afflictions, and barely made it through. Despite these small victories, Juniper's doctor pointed out that in order to stop the infection in her stomach, they might have to operate. A risky and novel procedure for someone so small, Kelley and Tom did not know what to do. This could mean the end, or it could save Juniper's life. Having only performed the surgery on two other premature babies who were both twice Juniper's weight, the surgeon admitted that only one had survived. Kelley, Tom, and the doctors alike were reluctant to make a decision.

Then Juniper opened her eyes and declared herself, the sign for which Kelley and Tom had been waiting.

They went ahead with the surgery, and while the surgery failed to repair the damage, Juniper survived. Soon enough, though, she developed a clot in her heart, and because the surgery failed, feces started leaking out through her belly (French and French 2016). Week after week, Juniper's body rejected something new, did something it wasn't supposed to, or failed in some way. Persistent interventions did not seem to be working. Kelley first asked herself, and then Tom, if they should keep trying. Was it moral? Was it fair to Juniper? "Would we try to keep her alive? If she lived, would she walk or talk? Would she one day give us a look that said, *Why did you put me through this?*" (Benham 2012).

Epilogue: The Girl Who Lived

Day 196

Kelley, Tom, and Juniper left All Children's Hospital on October 25, 2011 after she had lived and grown up in the NICU for 196 days. They put her in her car seat and carried her out of the hospital for the first time: "Juniper wore sunglasses, but I can't imagine what she must have made of it when those doors slid apart and everything opened up in front of her. So much sun. All that sky" (French and French 2016, 305).

Present Day

At four years old, Juniper is a healthy, normal child. Kelley writes, “she is muddy boots, chipped fingernail polish, Eggo waffles, shrieking laughter, spilled glitter, pout-pout kisses, lost balloons. She rides horses, climbs rocks. Kicks the back of the passenger seat. Gestures wildly when she talks” (French and French 2016, 308). She is a budding gymnast, takes care of animals from the animal shelter, has eight chickens, and she frequently asks to hear the story of how she was born. Kelley and Tom took Juniper back to the NICU at All Children’s to show her where she grew up for the first 196 days. Juniper was fascinated, as adventurous and curious as she normally is. When peering inside the incubator, the doctor told Juniper that she had a beautiful heart (French and French 2016).

Juniper’s story illuminates the intersection of the NICU, medical decisions, the value and meaning of a baby’s life, and parenthood. While the innovations and procedures of the NICU have increased infant survival rates, they have in turn showcased the need for doctor-parent communication and discussion. This crucial relationship provides the best care possible to the baby. Still a gray zone, however, is the question of a baby’s viability, and whether viability translates to a chance at a fulfilling life. Unable to answer this question herself, Kelley Benham relies on her trust in the NICU doctors, as well as her hope for Juniper’s future. The combination of Kelley’s patience and resilience in the face of possibly losing her daughter showcases her true strength, both as a woman and a mother. And while not biologically related to her daughter, Kelley will pass this strength on to Juniper, the girl who lived against all odds.

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Appendix A: National Resuscitation Program (American Academy of Pediatrics 2017)

Neonatal Resuscitation Program® - Reference Chart

The most important and effective action in neonatal resuscitation is ventilation of the baby's lungs.

A Airway

- Place head in "sniffing" position.
- Suction mouth, then nose.

B Breathing

- If apneic, gasping, or HR <100 bpm, give PPV at 40–60 breaths/min.
- Listen for rising heart rate for first 15 seconds of PPV.
- If HR not rising and chest not moving with PPV, do MR, SOPA until chest moves with PPV for 30 seconds.
- Attach pulse oximeter; consider cardiac monitor.
- Intubate or place laryngeal mask and give PPV for 30 seconds prior to starting compressions.
- Use CO₂ detector after intubation or insertion of laryngeal mask.

C Circulation

- Start compressions if HR is <60 bpm after 30 seconds of PPV with chest movement. Check HR every 60 seconds.
- Cardiac monitor is preferred method for assessing HR during CPR.
- Give 3 compressions: 1 breath every 2 seconds. Use 100% oxygen.
- Compress one-third of the anterior-posterior diameter of the chest.

D Drugs

- Give epinephrine if HR is <60 bpm after 60 seconds of CPR.
- Caution: epinephrine dosage is different for ET and IV routes.

MR, SOPA Corrective Steps

M and R	Mask adjustment, reposition airway
S and O	Suction mouth and nose, open mouth
P	Pressure increase
A	Alternative airway (ET tube or laryngeal mask)

Endotracheal Intubation

Gestational Age (weeks)	Depth of Insertion at Lips (cm)	Weight (g)	ET Tube Size (ID, mm)
23–24	5.5	500–600	Size 2.5
25–26	6.0	700–800	<1,000 g or <28 weeks
27–29	6.5	900–1,000	Size 3.0
30–32	7.0	1,100–1,400	1,000–2,000 g or 28–34 weeks
33–34	7.5	1,500–1,800	Size 3.5
35–37	8.0	1,900–2,400	>2,000 g or >34 weeks
38–40	8.5	2,500–3,100	
41–43	9.0	3,200–4,200	3.5–4.0

Shaded table adapted from Kempey SE, Moreira JM, Petrone FL. Endotracheal tube length for neonatal intubation. Resuscitation. 2008;77(1):369–373.

Medications Used During or Following Resuscitation of the Newborn

Medication	Dosage/Route*	Wt (kg)	Total Volume (mL)	Precautions
Epinephrine 1:10,000 (0.1 mg/mL)	0.1 to 0.3 mL/kg Intravenous (preferred route)	1	0.1–0.3	Give rapidly; follow IV dose with 0.5–1 mL normal saline flush. Repeat every 3 to 5 minutes if HR <60 with chest compressions. After ET dose, may give IV epinephrine as soon as IV route is established.
		2	0.2–0.6	
		3	0.3–0.9	
		4	0.4–1.2	
	0.5 to 1 mL/kg Endotracheal (acceptable until IV established)	1	0.5–1	
		2	1–2	
		3	1.5–3	
		4	2–4	
Volume expanders Normal saline 0-negative PRBC	10 mL/kg IV	1	10	Not responding to steps of resuscitation and has signs of shock or history of acute blood loss. Give over 5 to 10 minutes.
		2	20	
		3	30	
		4	40	

*Note: Endotracheal dose may not result in effective plasma concentration of drug, so vascular access should be established as soon as possible. Drugs given endotracheally require higher dosing than when given intravenously.

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The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.