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SMALL BUT NOT FORGOTTEN:  
ADOCATING FOR LEGAL GUIDELINES  
IN THE INTENSIVE CARE OF  
PREMATURE INFANTS WHEN LEGAL  
GUIDANCE IS SCARCE.

Brandy Booth



### ABSTRACT

Currently there is a lack of legal guidance regarding the resuscitation and implementation of life-sustaining treatment for premature infants born in the gray zone of viability, causing inconsistency in hospital policy throughout the nation. This inconsistency negatively impacts the data collected, which is then heavily relied on by doctors to determine if a premature infant should or should not receive resuscitation and life-saving medical treatment. Amending the current statute governing preterm labor and delivery to create a consistent procedure throughout the United States will help with the collection of data, understand the factors that impact prematurity, protect the rights of parents to determine a child's medical treatment, and push for doctors to consider what other factors are involved when using a best interest assessment.

This Article analyzes some of the large gaps in the existing law and proposes amendments to an existing federal statute that will alleviate many of the problems these gaps create. The proposed language establishes a procedure for all hospital policies to incorporate, which will create a consistency in hospital practices throughout the country. This consistency will not only ensure that each child will be given an opportunity at life but will also help push doctors away from relying on skewed medical statistics, which are faulty due to the inconsistency in policies. Immediate resuscitation after birth will make certain that doctors are not basing decisions about whether or not to resuscitate an infant of off pre-birth estimations and incorrect diagnoses.

The proposed language also encourages doctors to take into account the best interest of the child and analyzes the current definition of best interest. Due to the lack of explicit factors from caselaw and statutes, this Article proposes possible factors that may be used and advocates

for a wholistic approach to this determination. The best interest of the child plays the biggest role during the determination of whether treatment should be continued or withdrawn, but this Article also pushes to protect the deeply rooted presumption that parents should have the right to determine the medical treatment of their children.

## I. INTRODUCTION

Sophie feels a small kick, and her hand instinctively flies to her swollen belly. She smiles. She finally became pregnant after years of trying, and just a few days ago she was told, “Congratulations, it’s a little girl!” by the ultrasound technician. A name has been chosen, and the paint on the walls of the spare bedroom has only just dried. Suddenly something doesn’t feel quite right.

The doctor at the hospital informs her that they have done all they can to stop the labor, but an infection was now threatening Sophie’s life—she would need to deliver this child immediately. The doctor tells her that the child is estimated to be twenty-two weeks of gestation, with a low possibility of survival. The doctor tells her that resuscitation for babies at this gestational age is unusual and not performed in this hospital. Because of her current condition, there was no way she could be stabilized for transport even if she knew of a different hospital that would perform resuscitation on the infant.

Sophie’s situation is, unfortunately, quite common. In the U.S. in 2017, there were more than three million children born, and over ten percent of these were premature.<sup>1</sup> Specifically, nearly twenty-six thousand infants were born under twenty-eight weeks of completed

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<sup>1</sup> Joyce A. Martin et al., *Births: Final Data for 2017* (no. 8), 67 NAT’L VITAL STATISTICS REPORTS 1, 2 (2018),

[https://www.cdc.gov/nchs/data/nvsr/nvsr67/nvsr67\\_08-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr67/nvsr67_08-508.pdf)

[hereinafter Martin (2017)]; Joyce A. Martin et al., *Births: Final Data for 2018* (no. 13), 68 NAT’L VITAL STATISTICS REPORTS 1, 4 (2019),

[https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_13-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf)

[hereinafter Martin (2018)].

gestation,<sup>2</sup> which includes infants born between twenty-two and twenty-five weeks gestation and considered to be in the “gray zone” of viability.<sup>3</sup> The number of premature infants has been increasing for the last four years.<sup>4</sup> Throughout the nation, hospitals are looking for legal guidance to drive the construction of hospital policies for premature birth, but this guidance is seriously lacking.<sup>5</sup>

This Article will bring to the forefront an issue that has long been pushed aside: who decides if a premature child will be given resuscitation efforts and have implementation of life-sustaining treatment, and where are the protections for a parent’s right to determine medical treatment for their children? Without a revision to the statutory law governing delivery and care of these premature infants, hospital policy and national statistics will continue to be skewed.<sup>6</sup> Revising the existing law is the best way to ensure a common policy will be implemented in hospitals throughout the

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<sup>2</sup> Martin (2017), *supra* note 1, at 9.

<sup>3</sup> Jessica Brunkhorst et al., *Infants of Borderline Viability: The Ethics of Delivery Room Care*, 19 SEMINARS IN FETAL & NEONATAL MED. 290, 290 (2014).

<sup>4</sup> Martin (2017), *supra* note 1, at 2; Martin (2018), *supra* note 1, at 4.

<sup>5</sup> *Delivery Room Emergencies*, 24 SEMINARS IN FETAL & NEONATAL MED. 1, 2 (2019).

<sup>6</sup> Bonnie H. Arzuaga & William Meadow, *National Variability in Neonatal Resuscitation Practices at the Limit of Viability*, 31 AM. J. PERINATOLOGY 521, 524, 526-27 (2013) (noting that there is lots of variation throughout the United States in regard to practitioners’ choice to resuscitate premature infants, and that legal obligations must stay up to date in order to be the most effective guidance for medical staff since the concept of human viability is evolving constantly.).

nation, parental decision making will be protected, and the infant's best interest assessment will be more thoroughly analyzed. This Article focuses on what is known as the "gray-zone" of premature birth: infants born from twenty-two to twenty-five weeks of completed gestation and considered to be on the edge of viability.<sup>7</sup> Part II of this Article will assess the widespread problem of premature birth in the United States by discussing current prematurity statistics, the historical evolution of the Neonatal Intensive Care Unit (NICU), and a basic overview of gestational age calculations. Part III of the Article will discuss two landmark cases from Wisconsin and Texas as well as the rules created by the respective courts. Part IV will follow with an analysis of the current definition of a child's best interest in regard to medical treatment decisions. The background of this Article will conclude in Part V, with an overview of the governing statute for the delivery, care, and research of premature birth, including relevant legislative history.

Part VI will lay out the proposed amendments to the existing statute governing delivery and care of premature infants. The benefits of these amendments will follow in Part VII, consisting of an in-depth analysis of the creation of consistency in hospital policy, what factors should be included in the best interest assessment, and how these amendments will protect the decision-making rights of parents.

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<sup>7</sup> Brunkhorst et al., *supra* note 3; James G. Anderson et al., *Survival and Major Morbidity of Extremely Preterm Infants: A Population-Based Study*, 138 PEDIATRICS 1, 1 (2016) (noting this is also known as the "limit of viability.").

## II. PREMATURE BIRTH —AN OVERVIEW

The field of medicine and neonatology can be difficult to understand, and a general knowledge of the practices used and statistics available can be helpful when diving into the world of premature infants. This section intends to provide a full overview of the prevalence of prematurity in the United States, the rapid evolution of the NICU, and the estimated gestational age factor relied on by physicians. This information will be helpful for the reader to understand the history and relevance of the later arguments made in parts VI and VII of this Article.

### A. Prematurity in the United States

The now-common issue of premature birth shows no intention of changing in the near future. Of the 3,855,500 births in the United States in 2017, 9.93%—approximately 382,851 infants—were born preterm.<sup>8</sup> A preterm birth is commonly defined as an infant born before thirty- seven weeks of completed gestation.<sup>9</sup> Babies born early preterm, meaning less than thirty-four weeks of completed gestation, was 2.7%—approximately 106,412 infants.<sup>10</sup> Infants born extremely preterm with less than twenty-eight weeks of completed gestation encompassed 0.67%, or approximately 25,832 infants.<sup>11</sup> According to

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<sup>8</sup> Martin (2017), *supra* note 1, at 2.

<sup>9</sup> *Frequently Asked Questions: Extremely Preterm Birth*, THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, <https://www.acog.org/Patients/FAQs/Extremely-Preterm-Birth> (last visited Jan. 31, 2020) [hereinafter THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS]; Martin (2017), *supra* note 1, at 7.

<sup>10</sup> Martin (2017), *supra* note 1, at 9.

<sup>11</sup> *Id.* at 37; *see also* THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, *supra* note 9.

National Vital Statistics, 2017 was the third year in a row in which the preterm birth rate rose, and the rate rose once more in 2018 from 9.93% to 10.02%.<sup>12</sup> Even with the dismal realization that prematurity rates continue to rise, there are still beacons of hope. One 2017 study showed that infants born from twenty-two to twenty-four weeks of gestation now have higher survival rates, including an increased chance of survival without neurodevelopmental impairment.<sup>13</sup> The study assessed newborns in groups based on their birth years.<sup>14</sup> The first group consisted of infants born in the years 2000 to 2003, the second group consisted of those born in 2004 to 2007, and the third group included infants born in 2008 to 2011.<sup>15</sup> The results of the study showed a six percent increase of overall survival rates, from thirty percent in the first group to thirty-six percent in the third group.<sup>16</sup> Among the groups, the mortality rate for infants in the third group were the lowest overall.<sup>17</sup>

Within this increased survival rate, there was also an increase in the rate of survival without neurodevelopmental impairment, from sixteen percent in the first group to twenty percent in the third group.<sup>18</sup> The rate of those infants who survived with neurodevelopmental impairment only experienced a slight increase, with fifteen percent in the

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<sup>12</sup> Martin (2017), *supra* note 1, at 2; Martin (2018), *supra* note 1, at 7.

<sup>13</sup> Noelle Younge et al., *Survival and Neurodevelopmental Outcomes among Periviable Infants*, 376 N. ENGL. J. MED. 617, 619 (2017).

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> *Id.* at 617.

<sup>17</sup> *Id.* at 620.

<sup>18</sup> *Id.*

first group and sixteen percent in the third group.<sup>19</sup> Based on these results, the authors of this study concluded that, between the years 2000 and 2011, the rate of survival without neurodevelopmental impairment increased for infants born at the borderline of viability, and the rate of those children born with neurodevelopmental impairment did not have significant change.<sup>20</sup> This study begins to show the significant trends of increasing survivability rates and less neurodevelopmental impairment in those infants who do survive.<sup>21</sup> If more premature babies are surviving, and more are surviving without an increase in neurodevelopmental issues, we must be doing something right medically.

### **B. History of the NICU**

In the case of these extremely preterm infants, resuscitation is generally required to restore life after birth.<sup>22</sup> The resuscitation an infant needs can be anything from the insertion of a tube into the infant's airway to help the baby breathe, to even taking steps to start the baby's heart.<sup>23</sup> Survival is unlikely without some form of resuscitation.<sup>24</sup> After the preterm infant has been stabilized, they are cared for in the Neonatal Intensive Care Unit (NICU), which is a specialized hospital nursery designed to provide around-the-clock care to sick or premature babies

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<sup>19</sup> Younge et al., *supra* note 13, at 620.

<sup>20</sup> *Id.* at 622.

<sup>21</sup> *Id.* at 619.

<sup>22</sup> THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, *supra* note 9.

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*



through the use of specialized doctors and technology.<sup>25</sup> These units provide the best, most technologically advanced care available to help the tiny infants achieve the best possible outcome.<sup>26</sup> It is important to note that each NICU is awarded a specific level based on what type of care they offer and the equipment available, but this Article will point to the NICU only in a general sense to avoid becoming too engrossed in the level system and the different technology or types of care in each unit.<sup>27</sup> Prematurity is far from a novel problem, with the first major step in care taking place prior to the 1900's, when two French obstetricians

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<sup>25</sup> *The Newborn Intensive Care Unit (NICU)*, MARCH OF DIMES, <https://www.marchofdimes.org/complications/the-nicu.aspx> (last visited Jan. 31, 2020).

<sup>26</sup> *Id.*; *The Neonatal Intensive Care Unit (NICU)*, STANFORD CHILDREN'S HEALTH, <https://www.stanfordchildrens.org/en/topic/default?id=the-neonatal-intensive-care-unit-nicu-90-P02389> (last visited Jan. 31, 2020); *Neonatal Intensive Care Unit (NICU)*, PREGNANCY, BIRTH & BABY, <https://www.pregnancybirthbaby.org.au/neonatal-intensive-care-unit> (Nov. 1, 2017).

<sup>27</sup> The level system for the NICU is beyond the scope of this Article but will likely play a large role in a hospital's ability to participate in the resuscitation and care of extremely premature infants. For more information on the NICU level system and how the proposals in this Article may be affected based on these differences, see *The Newborn Intensive Care Unit*, MARCH OF DIMES, *supra* note 25; see also *Levels of Medical Care for your Newborn*, MARCH OF DIMES, <https://www.marchofdimes.org/baby/levels-of-medical-care-for-your-newborn.aspx> (last visited Jan. 31, 2020).

used incubators for the first time.<sup>28</sup> The French obstetricians realized premature babies were usually unable to produce their own heat, but when put into an incubator, they could use their energy towards growth and weight gain instead.<sup>29</sup> This alone contributed to a twenty-eight percent decrease in infant mortality over a three year period.<sup>30</sup> Since this early beginning, doctors have been creating and modifying the technology used to give these tiny infants their best chance at life.<sup>31</sup>

The next large advancement for the care of premature babies came in 1922, when Dr. Julius Hess implemented a hospital-based intensive care unit at the Michael Reese Hospital in Chicago, which

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<sup>28</sup> Elizabeth Payne, *A Brief History of Advances in Neonatal Care* (Jan. 5, 2016), NICU AWARENESS, <https://www.nicuawareness.org/blog/a-brief-history-of-advances-in-neonatal-care>; Elizabeth A. Reedy, *Care of Premature Infants*, PENN NURSING, <https://www.nursing.upenn.edu/nhhc/nurses-institutions-caring/care-of-premature-infants/> (last visited Jan. 31, 2020).

<sup>29</sup> See Payne, *supra* note 28 (noting how the incubators were modeled similarly to chicken egg incubators of that time). Additionally, these incubators first appeared in national fairs. *Id.* The fees charged for admission to see these young babies went to funding of the incubators, so the premature infants were able to benefit from the new technology at no cost to their parents. *Id.* Many hospitals throughout Europe and America did not allow incubators to be used in the hospital, so the fairs were the only available option during this time until Dr. Martin Couney brought the fairs and incubated infants to the United States in the 1880s. *Id.* These fairs then continued into the 1940s. *Id.* See also Reedy, *supra* note 28.

<sup>30</sup> Payne, *supra* note 28.

<sup>31</sup> Payne, *supra* note 28; Reedy, *supra* note 28.

separated premature infants from the “normal newborns.”<sup>32</sup> He hired nurses whose sole responsibility was to provide care for the premature infants in the unit.<sup>33</sup> It wasn’t until after World War II, however, that the precursor to the modern NICU was created—the Special Care Baby Units.<sup>34</sup> The 1950s witnessed the survival of more, and smaller, premature babies which ignited the expansion of premature infant intensive care throughout the country.<sup>35</sup> During the time of Dr. Hess, the limit of viability was a child weighing around two pounds,<sup>36</sup> compare this to just seventy years later in the 1990’s, where infants as small as five hundred grams and about twenty-three weeks of gestational age were treated successfully.<sup>37</sup>

Between 1960 and 1990, neonatology became a medical subspecialty of pediatrics and sparked another advancement.<sup>38</sup> As public interest in premature infant care spiked, the advances in techniques, technology, and facilities began to evolve more quickly, followed by increased survival rates.<sup>39</sup> Researchers are hopeful that

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<sup>32</sup> Reedy, *supra* note 28.

<sup>33</sup> *Id.*

<sup>34</sup> Payne, *supra* note 28.

<sup>35</sup> *See* Reedy, *supra* note 28.

<sup>36</sup> *Id.*

<sup>37</sup> Payne, *supra* note 28.

<sup>38</sup> Reedy, *supra* note 28.

<sup>39</sup> *Id.* (noting that some of the new discoveries consisted of a direct relationship between the degree of prematurity and respiratory difficulties which lead to the implementation of oxygen and respirators in premature care); *see also* Hannah C. Glass, et al., *Outcomes for Extremely Premature Infants*, 120 ANESTHESIA & ANALGESIA 1337,

there will continue to be great leaps in scientific technology and medicine, leading to both higher survival rates and greater numbers of premature infants with fewer disabilities.<sup>40</sup>

### C. Estimated Gestational Age and the Role of Additional Factors in Survival Outcomes

When discussing the age of a pregnancy, it is common to refer to the gestational age, or the number of weeks, the woman has been pregnant.<sup>41</sup> Prenatally, the gestational age is calculated by the mother's recollection of her last menstrual period coupled with an ultrasound by the doctor.<sup>42</sup> Policies and clinical studies generally discuss gestational age as though it is precisely determined, but in most cases it actually cannot be.<sup>43</sup> The prediction of gestational age can be incorrect, at most, by a week or two, and even with the best estimation techniques, the prediction has a three to five day margin of error.<sup>44</sup> The only way to

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1339 (2015) (discussing studies researching the concentration of oxygen that should be used to maximize the survival rate of premature newborns and minimize possible disabilities).

<sup>40</sup> See generally Younge et al., *supra* note 13 (describing the changes between three groups of infants based on birth years and noting how technology has changed during the course of the study).

<sup>41</sup> See, e.g., Manya J. Hendriks & John D. Lantos, *Fragile Lives with Fragile Rights: Justice for Babies Born at the Limit of Viability*, 32 NATIONAL LIBRARY OF MEDICINE 205, 207 (2018) [hereinafter Hendriks & Lantos].

<sup>42</sup> *Id.*

<sup>43</sup> *Id.*

<sup>44</sup> *Id.*; see also Sadath A. Sayeed, *Peri-Viable Birth: Legal Considerations*, 38 SEMINARS IN PERINATOLOGY 52, 52 (2014) (citing

know the exact gestational age of a pregnancy is through the use of assisted reproduction technology, like invitro fertilization.<sup>45</sup> Additionally, the age of gestation is usually recorded as a completed week (instead of week and day), and is usually never rounded up.<sup>46</sup> So if an expecting mother is twenty-three weeks and three days of gestation, the gestational age of the pregnancy would typically be considered twenty-three weeks.<sup>47</sup> The calculation of gestational ages plays a large role in a physician's decision-making process when determining whether or not resuscitation should be attempted for a premature infant.<sup>48</sup> National statistics for survival organizes probabilities by gestational age, which is calculated by combining the statistics from reporting hospitals throughout the country of infants who survived at all different gestational ages.<sup>49</sup> Literature has shown that survivability is historically the main factor driving a physician's decisions regarding resuscitation and other life prolonging treatments, rather than other factors like the wishes of the parents and the child's

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F. Gary Cunningham et. al., *Williams Obstetrics*, Ch. 42: Preterm Birth (McGraw-Hill Medical et al. eds., 23rd ed. 2009)).

<sup>45</sup> Hendriks & Lantos, *supra* note 41, at 207.

<sup>46</sup> Glass et al., *supra* note 39, at 1338.

<sup>47</sup> *Id.* ("For example, an infant who is born at 32 weeks and 4 days is defined as being 32 weeks.").

<sup>48</sup> *See, e.g.*, Brunkhorst et al., *supra* note 3 (discussing the use of gestational age and its shortcomings).

<sup>49</sup> *See* Martin (2017), *supra* note 1.

future quality of life.<sup>50</sup> The Neonatal Research Network for Extremely Preterm Birth provides a calculator based on gestational age and national survival data that can be referred to when considering possible outcomes for infants.<sup>51</sup> This calculator includes an overview statement to inform the user that the calculator is not intended to be, and should not be used as, a definitive prediction of an individual infant's outcome, but should instead be used by health care providers as information about the possible outcomes based on standardized assessments and national data.<sup>52</sup> The factors included in the standardized assessments were the infant's gestational age, birth weight, sex, and whether or not this was a singleton birth.<sup>53</sup> The source reminds users that the calculator is merely for the purpose of providing a range of possible outcomes based on specific characteristics, but the decision for the future care of an infant should consider several other possible factors, which may have not been included in the standardized assessments, including the health of the mother.<sup>54</sup>

A retrospective study conducted in 2016 lays out a few of these

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<sup>50</sup> Andreea Gorgos et. al, *A Shared Vision of Quality of Life: Partnering in Decision-Making to Understand Families' Realities*, 29 PEDIATRIC RESPIRATORY REV. 14, 14 (2019).

<sup>51</sup> Overview, *NICHD Neonatal Research Network (NRN): Extremely Preterm Birth Outcome Data*, NATIONAL INSTITUTES OF HEALTH, <https://www.nichd.nih.gov/about/org/der/branches/ppb/programs/epbo> (last visited Jan. 31, 2020).

<sup>52</sup> *Id.*

<sup>53</sup> Use the Tool, *NICHD Neonatal Research Network (NRN): Extremely Preterm Birth Outcome Data*, NATIONAL INSTITUTES OF HEALTH, <https://www.nichd.nih.gov/research/supported/EPBO/use> (last visited Jan. 31, 2020) [hereinafter Use the Tool].

<sup>54</sup> *Id.*; See Anderson, *supra* note 7, at 3-4.

factors that play a role in a premature infant's possibility of survival other than predicted gestational age,<sup>55</sup> including maternal demographic characteristics, birth weight, and gender of the infant.<sup>56</sup> Studies have shown an increased chance of survival for female infants born between twenty-two to twenty-four weeks with a higher birth weight.<sup>57</sup> Additionally, those infants born between twenty-two and twenty-four weeks by c-section showed an increased rate of survival, but those infants born between twenty-five and twenty-eight weeks showed a lower chance of survival when delivered by c-section.<sup>58</sup> Factors like maternal race, age, and education also play a role in determining the rate of survival of an infant.<sup>59</sup> The study showed that those premature infants born to mothers who were non-Hispanic, over the age of thirty-four, and with more than twelve years of education had increased survival rates.<sup>60</sup> Additionally, singleton births had a significant difference in their survival rates when compared to plurality births.<sup>61</sup>

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<sup>55</sup> See Anderson, *supra* note 7.

<sup>56</sup> *Id.* at 8.

<sup>57</sup> *Id.* at 4 (citing Table 4 and 5) (citing Jon E. Tyson et al., *Intensive Care for Extreme Prematurity – Moving Beyond Gestational Age*, 358 N. ENGL. J. MED. 1672 (2008)).

<sup>58</sup> *Id.*

<sup>59</sup> *Id.* at 8.

<sup>60</sup> *Id.* at 4-5.

<sup>61</sup> The American College of Obstetricians and Gynecologists, *Perivable Birth: Interim Update*, 127 OBSTETRICS & GYNECOLOGY 157, 159 (2016) (Plurality refers to “[t]he number of fetuses delivered, live or dead, during the pregnancy.”).

### III. LANDMARK CASELAW FROM TEXAS AND WISCONSIN CREATING RULES TO GOVERN RESUSCITATION AND LIFE-SUSTAINING TREATMENT FOR PREMATRUE INFANTS

As of today, a bright line rule to govern when there should be resuscitation efforts for a premature child does not exist, nor is there ample case law or statutory law to determine who should make these decisions.<sup>62</sup> Hospitals throughout the nation have enacted individual policies, which causes dramatic differences between local and regional policies.<sup>63</sup> Premature birth generally tends to be an emergency, and there is a high possibility the parent will be incompetent, so the question regarding who should be making the life-or-death decision is problematic.<sup>64</sup> Should this decision rest with the parents, as is deeply rooted in our law?<sup>65</sup> Or should this decision go to those trained and highly educated about the human body and even premature babies specifically? Texas and Wisconsin courts have addressed this issue and have created two different rules for this very situation.<sup>66</sup>

#### A. Emergent Circumstances and a Physician's Ability to Avoid Liability in Texas

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<sup>62</sup> See, e.g., Brunkhorst et al., *supra* note 3, at 24.

<sup>63</sup> *Id.* at 2 (citing Matthew A. Rysavy et al., *Between-Hospital Variation in Treatment and Outcomes in Extremely Preterm Infants*, 372 N. ENGL. J. MED. 1801, 1801-11 (2015)).

<sup>64</sup> See generally Sayeed, *supra* note 44 (discussing the ethical and legal issues surrounding decision making in the delivery room in the case of resuscitation and life-sustaining treatment to premature infants).

<sup>65</sup> Miller *ex rel.* Miller v. HCA, Inc., 118 S.W.3d 758 (Tex. 2003).

<sup>66</sup> See generally *id.*; Montalvo v. Borkovec, 647 N.W.2d 413 (Wis. Ct. App. 2002).



In 2003, the Supreme Court of Texas created the emergent circumstances rule, allowing a physician to provide life-sustaining treatment to a child without prior consent from the parents.<sup>67</sup> In the case of Sidney Miller, the Court was asked to define the respective roles of parents and doctors when deciding the medical treatment of a premature child with an uncertain prognosis.<sup>68</sup>

About four months prior to her projected due date, Karla Miller was admitted to the Woman's Hospital of Texas in premature labor.<sup>69</sup> Karla was assessed immediately, and the doctors determined that her child was approximately twenty-three weeks gestation.<sup>70</sup> After initially attempting to stop the labor, the doctors realized that Karla had developed an infection that endangered her own life, and she would instead need to be induced.<sup>71</sup> The doctors explained the situation, to which Karla and her husband Mark decided there should be no heroic measures to save the child.<sup>72</sup> Later, hospital doctors and administrators held a separate meeting and determined there was a hospital policy that required resuscitation of a child weighing over 500 grams.<sup>73</sup> A neonatologist would need to be present at birth to assess, at that time, the child's condition and determine if resuscitation would be

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<sup>67</sup> *Miller*, 118 S.W.3d at 767-68.

<sup>68</sup> *Id.* at 765.

<sup>69</sup> *Id.* at 758.

<sup>70</sup> *Id.*

<sup>71</sup> *Id.*

<sup>72</sup> *Id.*

<sup>73</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 762 (Tex. 2003).

appropriate.<sup>74</sup> Hours later, Sidney Miller was born and successfully resuscitated against the wishes of her parents.<sup>75</sup> Sidney was seven years-old when this case was argued.<sup>76</sup> Due to a brain hemorrhage that occurred during the first few days of life, Sidney suffered from severe disabilities including the inability to “walk, talk, feed herself, or sit up on her own.”<sup>77</sup>

The Court reasoned that in an emergency, even with actual notice of parental refusal to consent, a doctor may still provide life-saving medical treatment to a child.<sup>78</sup> This exception is due to a lack of time to consult the parents, or in the event the parents and doctor disagree on the treatment, to seek court intervention.<sup>79</sup> Here, the premature birth of Sydney Miller was an emergency, so according to the Court, receiving parental consent to treatment was not implied.<sup>80</sup> The emergent circumstances exception acknowledges that any harm that may come from the proposed treatment would be greatly outweighed by the failure to treat. The outcome of withholding treatment under these circumstances would be, almost certainly, death.<sup>81</sup>

Although the Court acknowledges the presumption reflected in law and social concepts that parents are generally seen as the appropriate decision-makers for their children, they advise that there are limits.<sup>82</sup> In

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<sup>74</sup> *Id.* at 762.

<sup>75</sup> *Id.* at 762–64.

<sup>76</sup> *Id.* at 764.

<sup>77</sup> *Id.*

<sup>78</sup> *Id.* at 767–68.

<sup>79</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 768 (Tex. 2003).

<sup>80</sup> *Id.* at 768.

<sup>81</sup> *Id.* (citing *Canterbury v. Spence*, 646 F.2d 772, 788-89 (D.C. Cir. 1972)).

<sup>82</sup> *Id.* at 766 (citing *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944)).

the case of Sydney Miller, one of the reasons Karla and Mark’s decision making was limited had to do with several doctors testifying about their inability to make any determination about treatment prior to seeing the child at birth, as any prognosis would be mere speculation.<sup>83</sup> “[T]he sooner treatment was provided, the better chance Sidney had for survival without brain damage or, at least, without further brain damage.”<sup>84</sup> Although the right for parents to refuse medical treatment for their children has been deeply rooted in our law, Texas now recognizes the emergency circumstances exception, which greatly impacts the liability of attending physicians.<sup>85</sup>

### **B. Absent a Persistent Vegetative State, Parental Decision Making is Superseded by State and Social Interests**

The Wisconsin Appellate Court shows a slightly different ideology that mainly revolves around a significant State interest in the child, and the continuous “damned” status in which physicians are placed.<sup>86</sup> The court notes how, although physicians have a commitment to the preservation of life, those doctors placed in a situation that requires them to determine whether or not resuscitation is appropriate might be sued no matter what they choose to do—failing to resuscitate an infant they believe is not viable or resuscitating an infant that they believe is viable.<sup>87</sup> With these considerations in mind, the court

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<sup>83</sup> *Id.* at 769.

<sup>84</sup> *Id.* at 770.

<sup>85</sup> *See Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 770 (Tex. 2003).

<sup>86</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413, 419 (Wis. Ct. App. 2002).

<sup>87</sup> *Id.* at 421.

ultimately found that parents do not have the ability or the right to decide whether life-sustaining treatment should be withheld or withdrawn from their child.<sup>88</sup>

When Montalvo was admitted to St. Mary's Hospital in preterm labor, doctors calculated the baby's gestational age to be twenty-three weeks and three days with an estimated weight of 679 grams.<sup>89</sup> After unsuccessful attempts to stop the premature labor, Montalvo underwent a cesarean section procedure (c-section), and a neonatologist successfully performed life-saving resuscitation for the child.<sup>90</sup> The complaint filed against the doctors alleged that the Montalvos were not fully informed of the risks facing a child born at twenty-three weeks of gestation.<sup>91</sup> The trial court judge pointed to Wisconsin law, noting that the interest of the community to protect children and the physician's interest in the preservation of life overrides a parent's decision.<sup>92</sup>

The Appellate Court reviewed the law in Wisconsin governing informed consent, which stated that a physician is required to disclose any information a reasonable person would find necessary to make an intelligent decision regarding diagnosis and treatment options.<sup>93</sup>

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<sup>88</sup> *Id.* at 419.

<sup>89</sup> *Id.* at 415-16.

<sup>90</sup> *Id.* at 416; see also *C-Section Complications for Mother & Baby*, AMERICAN PREGNANCY ASSOCIATION, <https://americanpregnancy.org/labor-and-birth/cesarean-risks/> (Aug. 1, 2015) (defining a c-section as the process of making an incision in the woman's abdomen in order to extract the child and noting the risks for both mother and child).

<sup>91</sup> *Id.* at 416.

<sup>92</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413, 416 (Wis. Ct. App. 2002).

<sup>93</sup> *Id.* at 417 (citing *Kuklinski v. Rodriguez*, 555 N.W.2d 869 (Ct. App. 1996); WIS. STAT. § 448.30).

However, this duty did not include the disclosure of information during emergency situations in which the patient is either incapable of consenting, or the possible harm of administering the treatment to the patient outweighed the possible harm from not providing any treatment.<sup>94</sup> In short, a physician must disclose information based on what a reasonable person in a similar position would need to know in order to make an informed decision, but this is contingent on the circumstances of the given case, especially if there is an emergency.<sup>95</sup>

The appellate court gave two reasons why the informed consent process was not applicable in this case.<sup>96</sup> First, without a situation in which the child is in a persistent vegetative state, a parent's right to decide whether or not an infant should receive resuscitation and implementation of life-sustaining treatment does not exist.<sup>97</sup> It was undisputed that the child was not in a vegetative state, therefore the option to withhold life-sustaining treatment did not exist.<sup>98</sup> Second, the circumstances did not trigger the informed consent process due to the United States Child Abuse Protection and Treatment Act (CAPTA) of 1984.<sup>99</sup> A provision under CAPTA prohibits withholding any medical treatment from a disabled infant with a life-threatening condition.<sup>100</sup>

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<sup>94</sup> *Id.*

<sup>95</sup> *Id.* at 418 (citing *Johnson v. Kokemoor*, 545 N.W.2d 495 (Wis. 1996)).

<sup>96</sup> *Id.*

<sup>97</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413, 419 (Wis. Ct. App. 2002).

<sup>98</sup> *Id.*

<sup>99</sup> *Id.* (citing PUB. L. NO. 98-457, 98 WIS. STAT. § 1749 (codified at 42 U.S.C. §5101 et seq.)).

<sup>100</sup> *Id.* at 419 (citing 45 C.F.R. § 1340.15(b)(1)).

Therefore, CAPTA specifically prohibits a parent from choosing to withhold life-sustaining treatment to their child.<sup>101</sup> The court also pointed out that withholding the treatment would have actually been more harmful than the treatment itself.<sup>102</sup> The appellate court quoted the district court's reasoning that "[this] was a life or death situation. When a child is not breathing there is no time ... any amount of loss of oxygen could be devastating to the child."<sup>103</sup>

The appellate court concluded by referencing *Burks v. St. Joseph's Hospital* and the "damned if you do, damned if you don't" situations physicians are faced with when they make choices regarding resuscitation measures.<sup>104</sup> This reflects the idea that a doctor will be blamed for her actions no matter her choice – whether she decides to resuscitate the infant or not.<sup>105</sup> In *Burks*, a claim was brought against a physician who chose to not resuscitate a premature child based on his judgment that the premature child was not viable.<sup>106</sup> "If treating physicians can be sued for failing to resuscitate a baby they feel is not viable, and for resuscitating a viable baby such as [the Montalvo child], they are placed in a continuing 'damned' status. The public policy of Wisconsin does not tolerate such a 'lose-lose' enigma."<sup>107</sup>

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<sup>101</sup> *Id.* at 419.

<sup>102</sup> *Id.* at 420.

<sup>103</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413, 420 (Wis. Ct. App. 2002).

<sup>104</sup> *Id.* at 421.

<sup>105</sup> *Id.*

<sup>106</sup> *Id.* (citing *Burks v. St. Joseph's Hosp.*, 596 N.W.2d 391, 392 (Wis. 1999)).

<sup>107</sup> *Id.* at 421.

#### IV. THE CURRENT DEFINITION FOR THE “BEST INTERESTS” OF A CHILD IN REGARD TO MEDICAL TREATMENT

As the Texas Supreme Court stated, the presumption that a fit parent will act in their child’s best interest is deeply rooted in our law, but also has its limits.<sup>108</sup> Courts generally try to look at the best interest of the child when making these decisions, but the factors for the analysis will vary between each court and jurisdiction.<sup>109</sup> Overall, courts tend to remain non-specific and vague about what factors or standards they used in their determination, and how these assessments should be done moving forward.<sup>110</sup>

One factor both the Supreme Court of Texas and the Wisconsin Appellate Court include in their analyses relates to the presumption that the continuation of life is in the best interest of all children.<sup>111</sup> The Appellate Court in *Montalvo* incorporated this factor when it explained that withdrawing or withholding life-saving medical treatment is never in the child’s best interest unless the child is in a

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<sup>108</sup> *Troxel v. Granville*, 530 U.S. 57, 58 (2000) (discussing how the presumption destroys any reason for the State to question the parent’s ability to make these decisions and insert itself into the private life of a family).

<sup>109</sup> See, e.g., Neera Bhatia & Mirko Bagaric, *Best Interests of Neonates: Time for a Fundamental Re-Think*, 20 J.L. & MED. 852 (2013).

<sup>110</sup> See, e.g., *id.* (discussing how the criteria is opaque).

<sup>111</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003); *Montalvo v. Borkovec*, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002).

persistent vegetative state.<sup>112</sup> If the child is not in a vegetative state, the interests of the State and the public are satisfied by the continuation of the child's life.<sup>113</sup> The factor is explicitly stated by the Supreme Court of Texas when they note that "[t]here is a presumption that continued life is in the best interests of a patient," and "[i]t is impossible for the courts to calculate the relative benefits of an impaired life versus no life at all."<sup>114</sup>

In their own case regarding medical treatment of a minor, the Massachusetts Supreme Court detailed several factors that it believed should be considered when assessing if medical treatment would be in a child's best interest.<sup>115</sup> These factors included the extent of impairment of the patient's mental faculty; the prognosis both with and without the proposed medical treatment; the possible side effects of the medical treatment; the complexity, risk, and novelty of the proposed treatment; and the urgency of the decision.<sup>116</sup> Although the court lists these as possible factors to assist in the determination of medical treatment, they do not give any direction as to which of these factors are most desirable or which combination of factors would be best situated in answering these questions.<sup>117</sup> In fact, the Court states that "since the scientific underpinnings of medical practice and opinion are in a constant state of development, our opinion as to a particular set of facts may not be a

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<sup>112</sup> *Montalvo*, 647 N.W.2d at 421; *see also supra* Part III-B (discussing the court's decision in the *Montalvo* case and how the preservation of life outweighs withdrawal of treatment).

<sup>113</sup> *See Montalvo*, 647 N.W.2d at 421.

<sup>114</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 768 (Tex. 2003).

<sup>115</sup> *Custody of a Minor*, 385 Mass. 697, 709 (1982).

<sup>116</sup> *Id.* (quoting *Matter of Spring*, 380 Mass. 629 (1980)).

<sup>117</sup> *Matter of Spring*, 380 Mass. 629, 636–37 (1980).



reliable guide to the proper solution of a future medical problem.”<sup>118</sup> The statutory definition of the withdrawal of medical treatment also includes factors that may be helpful during the determination of the best interest of a child in regard to medical treatment.<sup>119</sup> The statute states, in part, that treatment is not required if the treatment: (1) is directed at an infant who is chronically and irreversibly comatose; (2) would only prolong death; (3) would not correct or improve all of the life-threatening conditions; (4) would be futile for the survival of the infant; or (5) would be in itself inhumane in light of the circumstances.<sup>120</sup> More recently, the best interest test has evolved into an assessment of the future quality of life for the premature child.<sup>121</sup> Quality of life is defined, in its simplest form, as a person’s perception of where they are in life in relation to their “culture and value system[,] in relation to [their] goals, expectations, standards, and concerns.”<sup>122</sup> In other words, a person’s perception of their satisfaction with their life.<sup>123</sup> Quality of life assessments are subjective and complex due the wide variability of things that may affect someone’s satisfaction with their life, including health, education, safety, and meaningful employment.<sup>124</sup> Of course, the premature infant’s lack of cognitive maturity to competently assess their medical needs for the determination of possible treatment makes a

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<sup>118</sup> *Id.*

<sup>119</sup> 42 U.S.C.A. § 5106g(a)(5) (West 2017).

<sup>120</sup> *Id.* §§ A-C.

<sup>121</sup> Bhatia & Bagaric, *supra* note 109, at 852.

<sup>122</sup> Andreea Gorgos et al., *supra* note 50, at 15.

<sup>123</sup> *Id.*

<sup>124</sup> *Id.*

quality of life assessment incredibly difficult.<sup>125</sup>

Those who would otherwise assist in making quality of life decisions, like doctors and parents, have difficulty calculating an ill or disabled child's quality of life due to the healthy persons general inability to accurately estimate the ill or disabled individual's perception of satisfaction with their life.<sup>126</sup> Studies show that doctors have an overall lower expectation about the quality of life for a premature infant.<sup>127</sup> Doctors tend to overestimate the mortality of premature infants and underestimate the rate of survival without handicaps.<sup>128</sup>

Additionally, studies have shown that children born preterm tend to perceive their quality of life similarly to a healthy child of the same age group's perception despite usually having poorer health.<sup>129</sup> Although courts depend heavily on the best interest assessment for a premature infant when considering serious medical treatment, the factors that create the assessment are largely undefined.

## V. THE EXISTING STATUTE GOVERNING PRETERM LABOR AND DELIVERY

Since its inception, the statute governing preterm labor and delivery has been driven by the long-term goal of prevention.<sup>130</sup> When

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<sup>125</sup> *Id.*

<sup>126</sup> *Id.*

<sup>127</sup> *Id.* at 14-15.

<sup>128</sup> Gautham K. Suresh, *In the 'Gray Zone,' A Doctor Faces Tough Decisions on Infant Resuscitation*, 32 HEALTH AFFS. 1841, 1845 (2013).

<sup>129</sup> Gorgos et al., *supra* note 50, at 15.

<sup>130</sup> *See generally* 152 CONG. REC. S8550-02 (daily ed. Aug. 1, 2006) (stating that the purposes of the statute are "to reduce preterm labor and delivery and the risk of pregnancy-related deaths and

it was proposed, the statute was intended to directly attempt to reduce the incidence of preterm labor and delivery, as well as reduce the risk of preterm pregnancy-related deaths and complications.<sup>131</sup> Based on this, the Legislature recommended that society work toward an evidence-based standard of care, the creation of which relies strongly on the ability to conduct research and collect data that can help doctors determine what may impact a mother's health or an infant's ability to survive.<sup>132</sup>

In order to work towards this evidence-based standard, the Legislature granted the Secretary of Health and Human Services the power to act through the Director of the Centers for Disease Control and Prevention (CDC) to conduct studies relating to premature labor and birth.<sup>133</sup> These studies were intended to shed light on the specific factors that may be playing a role in preterm labor and birth, which could then be studied further and used to create plans to not only improve the national tracking of the incidence of premature birth, but also assess what could be done to prevent it.<sup>134</sup> After the implementation of measures to prevent premature birth, the studies could then shift to assessing the impact of the prevention measures on both the child and the

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complications due to pregnancy, and to reduce infant mortality caused by prematurity.”).

<sup>131</sup> *Id.* at S8551; S. REP. NO. 109–298, at 2–4 (2006).

<sup>132</sup> 152 CONG. REC. S8550–02 (daily ed. Aug. 1, 2006); S. REP. NO. 109–298, at 2–4 (2006).

<sup>133</sup> 42 U.S.C.A. § 247b-4f (West 2019) (granting CDC the power to conduct research relating to preterm labor and delivery and the care, treatment, and outcomes of preterm and low birthweight infants).

<sup>134</sup> *Id.*

mother in a short and long-term respect, creating the evidence-based standard of care referenced in the language of the statute.<sup>135</sup>

## VI. PROPOSED AMENDMENTS TO THE EXISTING STATUTE REGULATING PRETERM LABOR AND DELIVERY

Amending the statute already in place for the research, care, and delivery of preterm children is the best option for protecting parental rights, reducing infant mortality rates, and working towards an evidence-based standard of care for both premature infants and their mothers. Medical articles that discuss premature labor and birth point to a lack of legal guidance in this area for hospital policy writers, which then leads to large differences in hospital policy throughout the nation.<sup>136</sup> Hospital policies are written with a number of different factors in mind, an important one being the implementation of any new law or regulation, which could include a change of provisions in an Act, changes for federal healthcare requirements, or new state laws and regulations.<sup>137</sup> This amended statute will provide guidance as to what should be done in the case of premature birth and will create

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<sup>135</sup> *See id.*

<sup>136</sup> *See, e.g.,* Brunkhorst et al., *supra* note 3, at 2 (discussing how there are large differences between hospital policies for resuscitation); Arzuaga & Meadow, *supra* note 6.

<sup>137</sup> Leah Robinson, *Hospital Policies and Procedures – Why Do We Need Them?*, POLICYMEDICAL, <https://www.policymedical.com/hospital-policies-and-procedures-why-need-them/> (last visited Jan. 31, 2021).

consistency in hospital policies throughout the nation.<sup>138</sup> The statutory language below consists of the combination of excerpts of the existing statute as they appear to date, and recommended language to expand the statute indicated in italics:

Amendment to 42 U.S.C.A. § 247b-4f:  
 Research relating to preterm labor and delivery and the care, treatment, and outcomes of preterm and low birthweight infants.<sup>139</sup>

*a. ~~Omitted~~ Guidelines Regarding Premature Birth and the Premature Child*  
*i. In the event of premature labor:*

*1. all reasonable attempts to resuscitate and stabilize the premature baby will be initiated; and*

*a. the premature child will be placed on life-sustaining support to allow for the physician to evaluate the child after birth and without attention to the predicted gestational age of the child; and until a time at which the infant's parent(s) are competent to make a decision regarding the continuation or withdrawal of life sustaining support for the infant.*

*ii. In the event the withdrawal of treatment has been determined to be in the best interest of the child, the physician shall:*

*1. continue administration of*

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<sup>138</sup> See, e.g., Brunkhorst et al., *supra* note 3, at 2 (noting the inconsistencies between hospitals regarding a hospital's approach to resuscitation).

<sup>139</sup> See 42 U.S.C.A. § 247b-4f (West 2019).

- medication and nutrition to the infant during the time of removal from life-sustaining treatment until death in order to limit the suffering of the infant; and*
2. *allow for the child's parent(s) to be present during the removal of treatment, until a time in accordance with other hospital policies regarding death of a patient.*
- iii. *In the event that the attending physician believes that a parental decision is in violation of any other statutory guidelines, including but not limited to any and all child abuse statutes or regulations, the physician may file with the court in their jurisdiction an emergency motion for a hearing before the court. There shall be no change in medical treatment prior to a ruling by the court.*
- b. Studies and activities on preterm birth
- (2) Report
- Not later than 2 years after November 27, 2013, and every 2 years thereafter, the Secretary of Health and Human Services, acting through the Director of the Centers of Disease Control and Prevention, shall submit to the appropriate committees of Congress reports regarding activities and studies conducted under paragraph (1), including any applicable analyses of preterm birth. Such report shall be posted on the Internet website of the Department of Health and Human Services. *The number of infants that were not given resuscitation shall appear as a separate*

*calculation in the report.*<sup>140</sup>

## VII. BENEFITS OF THE LANGUAGE OF THE PROPOSED AMENDMENTS— ENCOMPASSING THE RESEARCH, DELIVERY, AND CARE OF THESE TINY INFANS

Though simple, the proposed amendments will do more than align with the original purpose of the statute: they will create a better understanding of the survivability of premature newborns through standardized policies in hospitals throughout the nation and push to move away from reliance on gestational age. They will consider the child's best interest based on the fact that every child is unique and will assess factors like the gender of the child or the health of the mother and will protect the rights of parents to choose the medical treatment for their premature infant. The proposed amendments address and fill the existing gaps in the law that will lead to the reduced mortality rate caused by preterm birth and create the evidence-based standard of care the original statute called for.<sup>141</sup>

### A. The Creation of Consistency in Hospital Policy

Hospital policy writers will look to and incorporate any state or federal law related to the new policy they are creating.<sup>142</sup> Currently, hospital policy writers do not have a specific federal guideline to follow, allowing them to create the guidelines as they see fit, which may be

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<sup>140</sup> *See id.* (b)(2).

<sup>141</sup> 152 CONG. REC. S8550-02 (daily ed. Aug. 1, 2006); S. REP. NO. 109-298, at 3–5, 7 (2006).

<sup>142</sup> *See* Robinson, *supra* note 137.

based on national survival statistics broken down by gestational age.<sup>143</sup> This creates a circular problem.

In fact, due to the inaccuracies of statistical reporting for the survivability of infants as well as the lack of habit to perform resuscitation for this gestational age group, doctors do not actually know if an infant born a few days before the twenty-second gestational week could survive.<sup>144</sup> All that is known from the reported data at this point is that those infants born after the twenty-two week mark of completed gestation have a statistically significant possibility for survival with the help of intensive medical care.<sup>145</sup> This is due to the large influence local policy and practices have on the delivery and management of premature babies, creating regional differences in mortality rates, which are then generated into a national statistic and greatly relied on by doctors when making a determination about whether or not to resuscitate.<sup>146</sup> A study done in 2016 showed that in hospitals spanning the country, only 21% of infants born at twenty-two weeks of gestation were resuscitated compared to 64% of twenty-three week infants and 93% of twenty-four

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<sup>143</sup> See generally Brunkhorst et al., *supra* note 3, at 2, 5 n.9 (citing Matthew A. Rysavy et al., *Between-Hospital Variation in Treatment and Outcomes in Extremely Preterm Infants*, 372 N. ENG. J. MED. 1801, 1801–11 (2015) (noting the tremendous variability in treatment throughout the United States by gestational age)).

<sup>144</sup> Sayeed, *supra* note 44, at 52.

<sup>145</sup> *Id.* at 52, 55 n.2 (citing Barbara J. Stoll et al., *Neonatal Outcomes of Extremely Preterm Infants from the NICHD Neonatal Research Network*, 126 PEDIATRICS 443, 443–45 (2010)).

<sup>146</sup> Hendriks & Lantos, *supra* note 41, at 208; see generally Arzuaga & Meadow, *supra* note 6, at 524 (discussing the different gestational ages doctors throughout the nation have resuscitated and are willing to resuscitate).



week infants.<sup>147</sup> From the percentage of infants that are given resuscitation, only a percentage of those will survive.<sup>148</sup> The outcome is then combined with other data from hospitals throughout the country, eventually being analyzed into a national statistic.<sup>149</sup> Based on these statistics, policy writers may determine that the national survival rate for a twenty-two-week-old infant is too low to warrant the resuscitation procedures, leading to a one-hundred percent mortality rate at their hospital for all infants born at twenty-two-weeks gestational age, due to the lack of resuscitation efforts for children born at that gestational age.<sup>150</sup>

It may be easier to break the possibility of resuscitation efforts into three general groups. Group one consists of the hospitals that decide to attempt resuscitation for all twenty-two-week-old infants as their policy, which means that of the 100% of children given resuscitation, a certain percent will survive. Group two are those hospitals who allow the attending neonatologist to determine if a child should be resuscitated after performing assessments on the child at the time of birth.<sup>151</sup> Here,

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<sup>147</sup> Anderson et al., *supra* note 7, at 4.

<sup>148</sup> *See id.*

<sup>149</sup> Glass et al., *supra* note 39, at 1340 (drawing this assertion logically from Glass et al.'s example of survival statistics becoming skewed from studies that only included data from patients admitted to intensive care nurseries).

<sup>150</sup> *See id.* (noting that it would be illogical for centers with a 100% mortality rate to argue that treatment is futile).

<sup>151</sup> *See, e.g., Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 762, 770 (Tex. 2003) (noting that the doctors and administrators believed a

the surviving children will be a percentage out of the percentage of twenty-two- week-old infants who were given resuscitation efforts, which is only a percentage of those children born at that gestational age at that hospital. Group three are the hospitals who never initiate resuscitation to infants of twenty-two-weeks gestational age, leading to a 100% mortality rate. The reported statistics for the hospitals of all three groups will then be combined to create a national statistic for twenty-two-week-old premature infants, which will then be relied on by hospitals throughout the nation and may play a role when determining hospital policy amendments.<sup>152</sup>

This whole situation causes national statistics to be incredibly skewed. If hospitals in one region refuse to initiate resuscitation or refuse administration of life-saving treatment to infants of a certain gestational age, their mortality rate for infants of that gestational age would ultimately equal 100% because there would be no statistics of survival.<sup>153</sup> This data is then incorporated with the data of other regions who may initiate resuscitation of every child, or only a percentage of children, based on a decision after birth causing the statistics for

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neonatologist needed to determine at birth whether resuscitation was appropriate or not).

<sup>152</sup> See Arzuaga & Meadow, *supra* note 6, at 525 (discussing the vast differences even in the United States due to differing opinions in each area); *Born Too Soon: The Global Action Report on Preterm Birth*, WORLD HEALTH ORGANIZATION, [https://www.who.int/pmnch/media/news/2012/201204\\_borntoosoon-report.pdf](https://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf) (last visited Jan. 31, 2021) (noting that one of the ways to get better quality data is through standard definitions and consistency in reporting).

<sup>153</sup> Hendriks & Lantos, *supra* note 41, at 207.

survivability to be skewed.<sup>154</sup> The situation is simple: if babies at twenty-two or twenty-three weeks are not treated, then babies at that gestational age will not survive.<sup>155</sup> This circular problem is the reason why the health profession does not actually know the probability of survival for a twenty-two week infant.<sup>156</sup>

The proposed amended language includes the requirement of immediate resuscitation efforts and implementation of life-sustaining treatment in order to stabilize the premature infant until such a time the doctor may fully assess the infant, fully inform the parents, and ensure the parents are competent to make a decision regarding the ongoing medical treatment of their child.<sup>157</sup> Every second used while making the decision whether or not to attempt resuscitation and implement life-saving treatment is another moment that child may not have oxygen leading to increasingly severe disabilities or even death.<sup>158</sup> The proposed amendments align with Wisconsin's need to protect doctors from the constant "damned" status by removing the doctor from the in-the-moment decision regarding whether or not the child should be resuscitated and given treatment.<sup>159</sup> The doctors will never need to question whether or not to act, allowing them to immediately attempt resuscitation and implement life-support to stabilize the newborn. A policy will make the decision rather than the doctor, removing them

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<sup>154</sup> *Id.* at 207–08; Suresh, *supra* note 128, at 1845.

<sup>155</sup> Hendriks & Lantos, *supra* note 41, at 207.

<sup>156</sup> *Id.* at 208.

<sup>157</sup> *See supra* pp. 14–15.

<sup>158</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 768 (Tex. 2003).

<sup>159</sup> *Montalvo v. Borkovec*, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002).

from the constant “lose-lose enigma.”<sup>160</sup> Once the child has been stabilized, the doctor then has the opportunity to fully assess the newborn, gather information and explore possible options tailored to that specific child, relaying this fully to the parents in a way that is tailored to their situation so they may make a decision about the continuation or withdrawal of treatment.<sup>161</sup>

The proposed language will have hospitals throughout the nation performing the same procedures in the case of preterm birth, making national policies consistent.<sup>162</sup> When all hospitals use the same procedures, there will be fewer variables that impact the survival rates of babies in the gray zone of viability.<sup>163</sup> Overall knowledge of a child’s ability to survive will be increased and infant mortality will decrease due to more babies receiving treatment.<sup>164</sup> Those infants who would have otherwise survived with treatment will be given a chance at life.<sup>165</sup> Besides, “[a] peri- viable neonate faces an all or nothing existential question. [The child] is either going to be 100% dead or 100% alive. Should it matter [] whether [the child’s] chance[s] of survival is 5%,

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<sup>160</sup> *Id.*

<sup>161</sup> *See supra* pp. 14–15 (noting how doctors will resuscitate and stabilize the infant, followed by an assessment of the child post-birth). The best way for a doctor to inform the parents about the infant’s situation and possible outcome is outside the scope of this Note.

<sup>162</sup> *See id.* (noting that all hospitals will be implementing this policy in similar ways, leading toward consistency).

<sup>163</sup> *See* Brunkhorst et al., *supra* note 3, at 291 (noting that it is reasonable to expect an increase in survival rates when there are increases in attempts at resuscitation).

<sup>164</sup> *See id.*

<sup>165</sup> *See id.*

10%, or 50%?”<sup>166</sup>

The proposed amended language includes an additional requirement that doctors report the number of any infants not given resuscitation efforts as separate data from the number of infants who received resuscitation and either survived or did not survive. This will cause the national statistics to more accurately reflect the increase in survival rates because the number of infants who do not receive resuscitation will not be included in the overall survival statistic calculation, skewing the statistics to a lower percentage when the child was not actually given any treatment. Although doctors should rely on factors that are not the estimated gestational age of the infant, it is still important to report the rate of survival across hospitals nationally in order to track progress and build our understanding about what technology and care may or may not be beneficial to the survival of premature infants.<sup>167</sup>

The proposed language pushes away from a reliance on estimated gestational age as a reliable indicator of the probability that an individual infant may or may not survive.<sup>168</sup> As of now, there is no data to show that doctors are proficient at estimating the gestational age of an infant, as the estimation prior to birth may actually be off by two

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<sup>166</sup> Sayeed, *supra* note 44, at 54.

<sup>167</sup> See, e.g., M. Vento & O.D. Saugstad, *Resuscitation of the Term and Preterm Infant*, 15 SEMINARS FETAL & NEONATAL MED. 216 (2010) (detailing different technologies and procedures that have been and should be implemented for resuscitation of premature infants).

<sup>168</sup> See *supra* pp. 14-15 (pushing towards factors other than gestational age while the doctor is assessing the infant).

weeks in either direction.<sup>169</sup> This means that if a doctor estimates a child is twenty-four weeks gestational age in the womb, the actual gestational age may be anywhere between twenty-two and twenty-six weeks of completed gestation, which can only be accurately determined after birth.<sup>170</sup> There is also a lack of data to suggest that gestational age is at all predictive of the infant's long-term health and survival.<sup>171</sup>

Many doctors have confessed that they cannot give a reliable prognosis before a child is born.<sup>172</sup> When attempting to give a prognosis of an unborn child, the doctor is put into a position of making a determination for a patient they have never even seen.<sup>173</sup> Doctors must simply make their best guess, which includes their prediction of the infant's chance of immediate survival as well as long-term outcomes.<sup>174</sup> Dr. Gauntham K. Suresh recounts his personal experience of a mistaken first impression, stating how he "was glad [he] had not used [his visual

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<sup>169</sup> See Hendriks & Lantos, *supra* note 41, at 207; Brunkhorst et al., *supra* note 3, at 291 ("Dating based on last menstrual period or second trimester ultrasound could be discrepant by as much as two weeks. This wide variation in estimation of gestational age affects the prediction of survival and neurodevelopmental outcomes. Inaccurate dating greatly impacts a clinician's prognostication.").

<sup>170</sup> See Hendriks & Lantos, *supra* note 41, at 207.

<sup>171</sup> *Id.* at 209.

<sup>172</sup> See, e.g., Brunkhorst et al., *supra* note 3, at 291 ("Clinicians who provide prenatal consultation are in a unique position. They have to talk about the prognosis for a patient whom they have never seen. They have to make their best guess as to when the delivery will occur, the probability of survival, and predict long-term outcomes. . . .").

<sup>173</sup> See *id.*

<sup>174</sup> *Id.*

gestational age estimate] or any other immediate impression to make a snap decision about resuscitation.”<sup>175</sup> Prior to birth, Dr. Suresh estimated a child to be about twenty-three weeks gestational age, but when the child was born, she was actually between twenty-five and twenty-six weeks gestational age.<sup>176</sup> He continues later to say that he is “reminded of and humbled by how easy it is for doctors to make mistakes when they try to decide which baby lives or dies based on a last-minute ultrasound or how the baby looks in the delivery room.”<sup>177</sup> Life-support can always be withdrawn after it has been initiated, but allowing for a baby to die due to a mistaken prediction of gestational age would be a catastrophic mistake.<sup>178</sup>

As if that was not enough, the process of analyzing and publishing data creates a time lag that also causes flaws in statistics.<sup>179</sup> Medical technology is rapidly changing and advancing, and it is likely that an advancement in the technology used at the time of data collection will have already occurred by the time the data is analyzed and published.<sup>180</sup> The published statistics would then automatically become less accurate due to the advancement that has already happened, and the published data could not be fully applied to the new technology, as that is not the technology that bore those statistics.<sup>181</sup> Moving away from a

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<sup>175</sup> Suresh, *supra* note 128, at 1843-44.

<sup>176</sup> *Id.* at 1843.

<sup>177</sup> *Id.* at 1844.

<sup>178</sup> *Id.* at 1842.

<sup>179</sup> Brunkhorst et al., *supra* note 3, at 294; Hendriks & Lantos, *supra* note 41, at 207.

<sup>180</sup> Brunkhorst et al., *supra* note 3, at 294.

<sup>181</sup> *Id.*

reliance on gestational age broken down by these national survival statistics, doctors can instead assess the infant post-birth with an eye to the individual child's ability to survive, and not be hindered by skewed and outdated national statistics.<sup>182</sup>

The focus will shift to consider the possible impact of other factors for survival not relating to gestational age, like the sex of the child or the health of the mother.<sup>183</sup> Each individual infant is unique, and the possibility of survival will differ from child to child.<sup>184</sup> Even the calculator provided by the Neonatal Research Network for Extremely Preterm Birth Outcome Data reminds users that the data used by the calculator should not be the determining factor for the individual outcomes of an infant, but is merely to provide information about a range of outcomes of children born in one region of hospitals for a short period of years.<sup>185</sup> By resuscitating and initiating treatment to stabilize, each infant will have the opportunity to show their individual ability to survive.<sup>186</sup>

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<sup>182</sup> See generally *id.* (discussing how the time lag that may cause data to be skewed should be interpreted cautiously when applied).

<sup>183</sup> See *infra* Part VII-B (considering different factors that may play a role on survival of an infant).

<sup>184</sup> See generally Anderson et al., *supra* note 7 (discussing how other factors, like the gender of the child, plays a part in the survivability of the infant).

<sup>185</sup> Use the Tool, *supra* note 53.

<sup>186</sup> See Steven R. Leuthner, *Commentary: Decisions Regarding Resuscitation of the Extremely Premature Infant and Models of Best Interest*, 21 J. PERINATOLOGY 193, 194 (2001); Brunkhorst et al. *supra* note 3, at 291 (“If an arbitrary line were drawn at 23 weeks, the infant with the better likelihood of a favorable outcome would not even be given a chance.”).



The concern voiced by the Texas Supreme Court about the need to limit a parent's right to consent to a child's medical treatment, especially for those parents whose conduct raises to the level of abuse or neglect, is an important one that should still be addressed.<sup>187</sup> The proposed language includes a failsafe that will allow the State or doctor to intervene in parental decisions in a circumstance where a doctor believes a parent is making a decision that may be detrimental to that child's best interests.<sup>188</sup> Although a parent is deemed to be the person best situated to make these decisions, there may be times that the expertise of the doctor will be pushed aside by the emotions of the parent, and only a neutral body will be able to make the final determination based on the best interest of the child.<sup>189</sup> It is important to note here that this failsafe is specifically for situations occurring after the child has been born and medical treatment has been implemented as opposed to before or during birth. For example, a doctor believes that a parent is requesting the withdrawal of treatment from an infant who is responding well to treatment and otherwise likely to become a healthy infant, a doctor may file an emergency motion with the court. Conversely, if the child is not responding to treatment but parents are requesting all drastic measures be implemented to keep the child alive, a doctor may file an emergency motion with the court.

This failsafe is included in the proposed amendments because a child's best interest should remain in the forefront of every decision and should be the driving factor in the decision-making process. Although

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<sup>187</sup> Miller *ex rel.* Miller v. HCA, Inc., 118 S.W.3d 758, 766–67 (Tex. 2003).

<sup>188</sup> *Id.*

<sup>189</sup> See Sayeed, *supra* note 44, at 54.

the proposed amendments aim to protect the parent's right to choose their child's medical treatment, the decision is one of life or death of the infant, so the best interest of the child should always be the most important consideration.<sup>190</sup>

The rapid evolution of the NICU points to another theme in neonatal medicine: the more interested society is in these premature infants, the faster new technology will be created and implemented.<sup>191</sup> Once society took more of an interest in the outcome of premature babies, technology advanced more rapidly, with progressively smaller and sicker infants being successfully resuscitated.<sup>192</sup> With attempted resuscitation and implementation of life sustaining treatment for every premature birth starting at twenty-two weeks of completed gestational age, advancements in the technology used for their medical care will be introduced more consistently, and society will light a fire for discovering new and better medicines and technologies to help reduce infant mortality due to premature birth.<sup>193</sup> Doctors will have more opportunities to see what works best with these neonates to not only

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<sup>190</sup> *Id.* (discussing examples of considerations that should be made in the face of prematurity and how the infant's best interests are sometimes a great burden).

<sup>191</sup> See Reedy, *supra* note 28.

<sup>192</sup> See, e.g., *infra* Part II-B (discussing the rapid evolution of the NICU once society became more interested in premature infants).

<sup>193</sup> See generally Reedy, *supra* note 28; see also Payne, *supra* note 28 (noting how the NICU evolved more rapidly when society became more invested in the outcome of the premature infants).

keep them alive, but also to increase their chances of survival without long-term impairments.<sup>194</sup>

### **B. Best Interest Assessments Focusing on the Individuality of Each Infant**

In the instance of a gray zone premature birth, doctors and parents may not agree on the best course of action for the infant's medical treatment due to different priorities and values.<sup>195</sup> Parents tend to be guided by factors like hope, religion or spirituality, and the family unit as a whole, including other siblings or if this premature infant is their first child.<sup>196</sup> The doctor, on the other hand, may be more concerned with the child's likelihood of survival based on what the national statistics says the chance of survival is for a child of the same gestational age.<sup>197</sup> When it comes to studies of survivability, the data is not intended

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<sup>194</sup> Brunkhorst et al., *supra* note 3, at 291 (noting that it is reasonable for an increase in survival rates to come from an increase in attempts for resuscitation).

<sup>195</sup> Thierry Daboval, et al., *Shared Decision Making at the Limit of Viability: A Blueprint for Physician Action*, 11 PLOS ONE 1, 2 (2016).

<sup>196</sup> *Id.*; Leuthner, *supra* note 186, at 195; Teresa T. Moro et al., *Parent Decision Making for Life Support Decisions for Extremely Premature Infants: From the Prenatal through End-of-Life Period*, 25-1 J.

PERINATAL NEONATAL NURSING 52, 52-53;

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3085847/pdf/nihms275903.pdf> ("The mothers also reported that religion, spirituality and hope ... guided their decision making.").

<sup>197</sup> Leuthner, *supra* note 186, at 195; Sayeed, *supra* note 44, at 53 (citing John Kattwinkle et al., *Part 15: Neonatal Resuscitation*, 2010

to be predictive of the outcome of each individual infant, but should instead be used to provide a “range of possible outcomes based on specific characteristics.”<sup>198</sup> A generalized statistic cannot predict the outcome of an infant, and there is no way to predict that a child born at twenty-three weeks gestation “will be one of the 26 out of 100 who survive.”<sup>199</sup> Since parents and neonatologists are driven by different priorities, it is important that choices about medical treatment balances both the values and needs of the parents as well as medical determinations made by the doctor.<sup>200</sup>

Courts often refer to the best interest of the child when determining appropriate medical treatment options, but few courts explicitly state the factors or standards used in their analyses to reach their conclusions.<sup>201</sup> For example, both the Texas and Wisconsin courts came to the conclusion that the continuation of life was in the best interest of the children involved, but neither court stated what factors or process was used to lead them to this conclusion.<sup>202</sup> Even authors of medical articles advocate for a decision-making process that is based on an extremely premature infant’s best interest but rarely offer any

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*American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care*, 122 (suppl. 3) CIRCULATION, 909, 915 (2010)).

<sup>198</sup> Sayeed, *supra* note 44, at 52.

<sup>199</sup> Brunkhorst et al., *supra* note 3, at 294.

<sup>200</sup> Daboval et al., *supra* note 195, at 2; *see* Bhatia & Bagaric, *supra* note 109, at 852.

<sup>201</sup> Bhatia & Bagaric, *supra* note 109, at 852.

<sup>202</sup> *See* Miller *ex rel.* Miller v. HCA, Inc., 118 S.W.3d 758, 769 (Tex. 2003); *see* Montalvo v. Borkovec, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002).

possible factors or standards.<sup>203</sup> One author noted that some factors that help determine the best interest of a child includes family relationships, medical health, anticipated quality of life, and upbringing of the infant.<sup>204</sup>

Although the proposed amended language does not include specific factors, it does note that physicians should evaluate the child after birth with reliance on factors other than the estimated gestational age.<sup>205</sup> A precise, rigid rule is against the spirit of understanding that factors affecting survival is unique to each infant, and requiring a specific test by implementing it into the statute presents the possibility that a factor crucial to an infant for survival may not be taken into account.<sup>206</sup> Instead, the assessment of the child's best interest should consider a wholistic view of many different factors, and these factors should be discussed continuously in the health profession, and included statutorily in the form of contextual note in the statute itself.<sup>207</sup> Doctors should analyze the best interest of the child with the inclusion of factors that highly impact the possibility of survival for a premature infant, those

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<sup>203</sup> See, e.g., Leuthner, *supra* note 186; Bhatia & Bagaric, *supra* note 109, at 852 (noting the lack of legal guidance in this area and advocating for a “re-think” of the best interests test).

<sup>204</sup> Leuthner, *supra* note 186, at 197.

<sup>205</sup> See proposed amendment *supra* note 139-140 and accompanying text (noting that doctors should not rely on the gestational age during their assessment).

<sup>206</sup> See Bhatia & Bagaric, *supra* note 109, at 852.

<sup>207</sup> See generally Arzuaga & Meadow, *supra* note 6, at 524 (discussing different ways doctors determine whether or not to resuscitate an infant and what factors come into play generally).

stated by the Massachusetts court, those noted in existing statutory law, and those that consider the future quality of life of the individual infant.<sup>208</sup> This Article will not propose which of these factors will in fact be most important in an assessment, as there likely needs to be more research, but this section will include an overview of the possible factors that may be considered as opposed to gestational age. Proposing a rigid rule for what factors to consider would essentially put doctors back in the situation this Article is arguing that the health profession should get away from—a large reliance on a single factor.<sup>209</sup>

Due to the effect factors like maternal demographic characteristics, birth weight, gender of the child, and plurality of birth may have on an infant's outcome, it is important to weigh the best interest of the child with a wholistic view of these factors in mind.<sup>210</sup> By first considering factors like these, a doctor and parent will avoid applying an overarching belief that children born at a certain gestational age simply have a better (or worse) opportunity to survive.<sup>211</sup> For example, if an infant falls into a category that generally fares better than

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<sup>208</sup> See generally Arzuaga & Meadow, *supra* note 6, at 524; 42 U.S.C.A. §5106g(a)(5) (West 2019); Custody of Minor, 434 N.E.2d 601, 608 (Mass. 1982); Gorgos et al., *supra* note 49, at 14.

<sup>209</sup> See, e.g., Daboval et al., *supra* note 194, at 2 (noting that doctors consider probabilities of survival to be the primarily guiding factor when determining the child's best interest).

<sup>210</sup> See, e.g., Brunkhorst, *supra* note 3 at 291 (“The NICHD calculator underscores the importance of taking all. Factors into account and not instituting hard-and-fast gestational age cut-offs when making decisions about resuscitation and offering intensive care.”).

<sup>211</sup> See, e.g., Daboval et al., *supra* note 194, at 2 (noting that doctors consider probabilities of survival to be the primarily guiding factor when determining the child's best interest).

others, like a higher birth weight, doctors and parents can weigh other factors in a best interest assessment in favor of a better possible long-term outcome.<sup>212</sup> The assessment, however, should not conclude with an analysis of only these factors. A determination for the best interest of the child must go further than statistical medical evidence and look to the future life of the child and future medical implications.<sup>213</sup>

Factors stated by the Massachusetts court may be helpful in looking at the future medical implications for the child.<sup>214</sup> Beneficial factors include the prognosis of a child with and without the different medical treatments currently available, possible side effects from the proposed medical treatment options, and the complexity and risk of these treatments.<sup>215</sup> These factors specifically consider the available treatment options for the immediate future of the child, guaranteeing the parents and doctors are looking further than the current moment.

Usually, the continuation of life is considered to be in the best interest of a child; but there are times where the withdrawal of treatment

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<sup>212</sup> See Anderson et al., *supra* note 6 at 4, 8 (noting “that a higher mean birth weight and female sex were each highly associated with increased survival,” and “[d]ifferences in ... characteristics ... such as increased birth weight and female sex, demonstrate favorable predictors for survival.”).

<sup>213</sup> See Daboval et al., *supra* note 194, at 2 (discussing the need to consider the future of an infant and how decision making must exceed the scope of just the medical evidence for risks and benefits).

<sup>214</sup> Custody of Minor, 434 N.E.2d 601, 608 (Mass. 1982).

<sup>215</sup> *Id.*

should be considered or may even be more appropriate.<sup>216</sup> The statutory definition of withdrawal of medical treatment includes factors to ensure that parents and doctors at least consider and question whether withdrawal of treatment is in the infant's best interest.<sup>217</sup> What if the child ends up chronically and irreversibly comatose? What if the treatment actually does nothing to treat a life-threatening condition, and instead simply prolongs the death of the child? Would this treatment be inhumane? It's likely that a parent will be unable to even consider whether refusal to administrate treatment or the withdrawal of treatment is in the best interest of the child, especially during circumstances as stressful as premature birth. However, having an assessment that includes these types of factors can attempt to assist the parents in looking at the bigger picture, and hopefully prevent a decision being made based on raw emotions. It is likely that a parent will be unable to even consider whether refusal to administrate treatment or the withdrawal of treatment is in the best interest of the child, especially during circumstances as stressful as premature birth.<sup>218</sup> However, having an assessment that includes these types of factors can attempt to assist the parents in looking at the bigger picture, and hopefully prevent a decision being made based on raw emotions.<sup>219</sup>

Quality of life considerations should also be included in the best interest analysis but weighed with the understanding that the average healthy person has difficulty adequately estimating the future quality of

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<sup>216</sup> See, e.g., Miller, 118 S.W.3d at 758 (stating that the continuation of life is in the best interest of a child).

<sup>217</sup> 42 U.S.C.A. § 5106g(a)(5) (West 2019).

<sup>218</sup> See generally Gorgos et al., *supra* note 49, at 17 (noting that parents' emotions might play a large role in interpreting what is in their child's best interest).

<sup>219</sup> *Id.*



life of an ill or disabled child.<sup>220</sup> Using the factors mentioned above from the statute or current caselaw may assist here.<sup>221</sup> In a doctor's mind, the best interest analysis is usually a benefit versus burden assessment revolving around possible therapeutic intervention, with an unfortunate underestimation of the quality of life a disabled child may have.<sup>222</sup> Although this consideration should include part of the doctor's benefit versus burden analysis, encompassing the possibility that future handicaps may impact the child's life, but a heavier focus should be on the fact that the child has never known life any differently and children have the innate ability to adapt.<sup>223</sup> However, if a child has never known life differently and holds the innate ability to adapt, even the challenge of a future life with a physical disability or a cognitive handicap cannot be said to be worse for the child than death.<sup>224</sup>

Having a fluidity in the factors that are weighed to determine a

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<sup>220</sup> *Id.* at 14–15.

<sup>221</sup> *See, e.g.*, *Custody of Minor*, 434 N.E.2d 601, 608 (Mass. 1982); 42 U.S.C.A. § 5106g(a)(5) (West 2019).

<sup>222</sup> Sayeed, *supra* note 43, at 54 (citing A. Buchanan & D. Brock *Deciding for Others: The Ethics of Surrogate Decision-Making*, CAMBRIDGE U. PRESS (1989)); Frank A. Chervenak & Laurence B. McCullough, *Ethical Issues in Periviable Birth*, 37 SEMINARS PERINATOLOGY 422–424 (2013) (citing Hunt S. Leplege, *The Problem of Quality of Life in Medicine*, 278 J. AM. MED. ASS'N 47, 47–50 (1997)).

<sup>223</sup> Sayeed, *supra* note 43, at 54.

<sup>224</sup> *Id.*

child's best interest makes certain a wholistic analysis is used.<sup>225</sup> It is important that these factors not only include those for the future life of the child, but also factors that protect from suffering those infants who may be comatose or not responding to treatment.<sup>226</sup> The proposed amendments emphasize that each child is unique and does not give a list of factors to consider because a strict analysis would be contrary to the spirit of assessing the infant individually and must reserve a degree of flexibility.<sup>227</sup> Statistics of viability, survivability, and the possibility of disability cannot predict the individual outcome for each specific infant.<sup>228</sup>

### **C. Protecting a Parent's Right to Decide the Medical Treatment of the Child**

The birth of a premature infant is stressful, and the looming life-or-death decision a parent must make next is even more so.<sup>229</sup> Mothers are likely to be scared, anxious, and heavily medicated, creating an inappropriate setting for a conversation between parent and doctor about an imminent life-or-death decision for the child.<sup>230</sup> A parent is unable to

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<sup>225</sup> See, e.g., Brunkhorst, *supra* note 3 at 291 (“The NICHD calculator underscores the importance of taking all. Factors into account and not instituting hard-and-fast gestational age cut-offs when making decisions about resuscitation and offering intensive care.”).

<sup>226</sup> See *Custody of Minor*, 434 N.E.2d 601, 608 (Mass. 1982); 42 U.S.C.A. § 5106g(a)(5) (West 2019).

<sup>227</sup> Bhatia & Bagaric, *supra* note 109, at 852.

<sup>228</sup> Brunkhorst et al., *supra* note 3, at 294.

<sup>229</sup> See, e.g., Hendriks & Lantos, *supra* note 41, at 212 (discussing some of the emotional choices parents must make following the premature birth); see Suresh, *supra* note 128, at 1845.

<sup>230</sup> Suresh, *supra* note 128, at 1845.

investigate their current doctor's opinion.<sup>231</sup> The option to receive a second opinion is nonexistent.<sup>232</sup> Parents are forced to make an immediate decision.<sup>233</sup> The proposed amendments intend for hospitals to adopt the practice of resuscitation and stabilization of the infant in every situation, followed by assessment by the doctor, and the presentation of all information to the parents, which will then alleviate the stress of making a life-or-death decision at the time of birth.<sup>234</sup> A parent's decision making right will essentially be protected until such a time that the parent is competent.<sup>235</sup>

The rights of parents to make the decisions about their child's medical treatment is deeply rooted in our law and society,<sup>236</sup> and a parent's decision about the premature infant's ongoing medical treatment is no exception. Studies have shown that, when given the choice, mothers choose to initiate life-saving care for their premature babies even with the understanding of the possibility of death.<sup>237</sup> This

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<sup>231</sup> Rebecca Cooper, *Delivery Room Resuscitation of the High-Risk Infant: A Conflict of Rights*, 33 CATH. LAW. 325, 328 (1990).

<sup>232</sup> *Id.*

<sup>233</sup> *Id.*

<sup>234</sup> *See supra* pp. 14–15 (noting the practice of resuscitation, stabilization, and then assessment of the child).

<sup>235</sup> *See supra* pp. 14–15 (noting that a parent will still have the ability to make a decision for their child because the doctor must wait until the parents are competent to inform them about their child).

<sup>236</sup> *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758, 766 (Tex. 2003).

<sup>237</sup> Hendriks & Lantos, *supra* note 41, at 212 (citing Kelley B. French, *Care of Extremely Small Premature Infants in the Neonatal Intensive*

is similar to the theme found in adult medicine, where someone learns of their loved one's poor or terminal prognosis, but still holds onto hope.<sup>238</sup> It is this common thread of hope and lack of regret that connects families who have an infant in the NICU. Research shows that throughout the stressful NICU admission, families remain "overwhelmingly grateful to the team providing care for their baby."<sup>239</sup>

Some critics believe that shared decision making between the parent and doctor is the best option for situations like premature birth, but this implies that there is a discussion between the parents and the physician regarding any criteria leading to a decision about the best interest of an infant born in this gray zone of survivability.<sup>240</sup> Additionally, there is evidence that any decisions made during the discussions between parent and doctor do not always correlate with how the delivery room is actually managed.<sup>241</sup>

Existing caselaw directly shows the corrosion of parental rights for medical treatment decision making.<sup>242</sup> The emergent circumstances

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*Care Unit: A Parent's Perspective*, 44 CLINICS PERINATOLOGY 275 (2017)).

<sup>238</sup> Marin Arnolds et al., *Worth a Try? Describing the Experiences of Families During the Course of Care in the Neonatal Intensive Care Unit when Prognosis Is Poor*, 196 J. PEDIATRICS 116, 120 (2018).

<sup>239</sup> *Id.* at 119-20.

<sup>240</sup> See Daboval et al., *supra* note 195, at 6.

<sup>241</sup> Arzuaga & Meadow, *supra* note 6, at 521 (citing Annie Janvier & Keith J. Barrington, *The Ethics of Neonatal Resuscitation at the Margins of Viability: Informed Consent and Outcomes*, 147 J. PEDIATRICS 579 (2005)).

<sup>242</sup> See, e.g., *Miller ex rel. Miller v. HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003) (arguing for physicians to initiate treatment to a child against the wishes of the parents in emergency circumstances).

view in Texas completely disregards the wishes of the parents and simply nods to the best interests of the child while instead giving the decision making power to the physician, who may be resting their decision on skewed statistics and an estimation of a prognosis before the child is even born.<sup>243</sup> The view in Wisconsin also disregards decision making on the part of the parent by preventing decisions about withdrawal of medical treatment absent the child being declared a vegetable; although Wisconsin does seem to consider that the continuation of medical treatment would not be in the best interest of the child if it would only prolong death.<sup>244</sup> No matter how you spin it, both States take most of the decision making away from the parents either due to a State interest or the life-or-death emergency circumstance the attending physician is placed in.<sup>245</sup> There are countless variables to consider during a premature birth and the implementation of treatment for the infant cannot be adequately discussed in this emergent timeframe.<sup>246</sup> Parents need to be fully informed of all options and possible outcomes for their infant, and a decision like this cannot be made at the drop of a hat. If a parent is not fully informed as to the infant's possibility of survival or the long-term effects of premature birth, a parent may not be able to make the best decision regarding the medical

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<sup>243</sup> See *id.*; Daboval et al., *supra* note 195, at 2 (discussing that doctors consider possibilities of survival as the primary guidance for best interest determinations).

<sup>244</sup> See *Montalvo v. Borkovec*, 647 N.W.2d 413, 413 (Wis. Ct. App. 2002).

<sup>245</sup> See *Miller*, 118 S.W.3d at 758; *Montalvo*, 647 N.W.2d at 413.

<sup>246</sup> See *supra* Part VII-B.

treatment for their child.<sup>247</sup> These proposed amendments encompass the deeply rooted historical presumption that parents are the appropriate decision maker and that parents should make medical decisions for their children.<sup>248</sup>

## VIII. CONCLUSION

Amending the existing statute regulating the research, delivery, and care of premature birth and premature infants is the best solution for bridging the existing gaps in the current law while conforming to the original purpose of the statute: The long-term goal of prevention through the movement to an evidence-based standard of care for preterm labor and birth.<sup>249</sup> The amendments will give hospital policy writers guidance on what should be implemented in their individual hospitals, creating consistency in the procedures used for all premature infants born in the gray zone of gestational age throughout the United States. With the implementation of a standardized policy, survival statistics will become more reliable due to the requirement of resuscitation for all infants in this gray zone until a time when the doctor has the opportunity to fully assess the infant, and parents are competent to make a decision regarding the continuing treatment of their newborn. Hospitals will report how many infants were not given resuscitation separately from the data of survival after initiating treatment, eliminating the possibility of a hospital having virtually a 100% mortality rate for infants born at a certain gestational age. Further, because of the requirement for

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<sup>247</sup> See, e.g., Anderson et al., *supra* note 7, at 8 (noting many factors that play a part in the outcome of survival for an infant).

<sup>248</sup> Miller *ex rel.* Miller v. HCA, Inc., 118 S.W.3d 758, 766 (Tex. 2003) (citing TEX. FAM. CODE §151.001(a)(6) (West 2003)).

<sup>249</sup> See S. REP. NO. 109-298, at 2–4 (2006); 152 CONG. REC. S8550-02 (daily ed. Aug. 1, 2006).

resuscitation, doctors will rely less on the national survival statistics due to the opportunity to fully assess the child after birth and stabilization and consider other factors that play a role in the infant's survival. The need to make a snap decision regarding resuscitation of an infant based on a pre-birth estimate created by faulty human memory and ultrasound technology will be nonexistent.

Although these amendments aim to protect a parent's right to choose the medical treatment for their child, this right comes second to the best interest of the child. The parent should not only be considering what is best for themselves and their families, but also asking themselves what would be in the best interest of their newborn. The assessment of a child's best interest will not be reliant on statistics of gestational age, but will encompass other factors, including the current medical treatment options, possible risks and side effects of these treatments, if the child is in a situation in which medical treatment would simply prolong death or not treat the underlying condition, and the future quality of life of the child.<sup>250</sup> These factors will work fluidly, ensuring doctors nor parents rely strictly on one or two of the factors to make their determinations.

In the face of the emergency of a premature birth, emotions and pressures are incredible. The amendments to the existing statute look to create a standard policy throughout the nation and to ensure every child is getting their own opportunity for survival. It is important to realize that, sometimes, following the chaos of the childbirth, "calm

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<sup>250</sup> See *Custody of Minor*, 434 N.E.2d 601, 608 (Mass. 1982); 42 U.S.C.A. §5106g(a)(5) (West 2019); Gorgos et al., *supra* note 50, at 14.

deliberation may reveal a devastatingly incorrect decision.”<sup>251</sup> The amendments protect doctors, parents, and premature infants from the irreversible incorrect decisions based on something as simple as estimated gestational age.

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<sup>251</sup> Rebecca Cooper, *Delivery Room Resuscitation of the High-Right Infant: A Conflict of Rights*, 33 CATH. LAW. 325, 330 (1990).