

# Brief to the U.S. Department of Health and Human Services regarding Perivable Birth

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### **About Life Legal Defense Foundation:**

The mission of Life Legal Defense Foundation (LLDF) is to give innocent and helpless human beings of any age, particularly unborn children, a trained and committed defense against the threat of death, and to support their advocates in the nation's courtrooms.

LLDF believes life begins at the moment of conception and does not end until natural death. We litigate cases involving the protection of life, including the protection of preborn babies who are targeted by a billion-dollar abortion industry. We also intervene in cases where people are denied life-sustaining care.

Our staff of full-time attorneys is involved in a wide range of cases—both civil and criminal—from the local courtroom all the way to the Supreme Court. We also have a vast network of pro-life attorneys nationwide that work with us, especially in cases where a local attorney is needed to file emergency motions.

We have represented notable leaders in the pro-life movement, as well as ordinary citizens, who have been fined, arrested, fired, or otherwise silenced because of their belief that human beings deserve protection from the moment of conception through natural death. Our client base also consists of family members desperate to see their loved ones given the life-sustaining medical treatment they deserve.

### **Project Background**

Life Legal was approached by two grass roots organizations that have been working diligently to pass state-level laws to protect babies from being discriminated against on the basis of age and/or disability. The groups originally contacted us to assist with complaints to the DHHS Office of Civil Rights. However, while conducting some initial research into the matter, we became aware of the significant medical progress in perivable resuscitation that has happened in the last 15 years. After consultation with obstetricians and neonatologists in our network, it is apparent that a thorough discussion of the current state of perivable births in America is warranted.

### **Goals of the Project**

In addition to advocating for six specific families who experienced denial of life-saving and life-sustaining care for their extremely premature babies, Life Legal seeks to offer an up-to-date summary of medical literature surrounding the advances in treating perivable babies, while analyzing gaps in success rates and identifying obstacles to treatment that should be addressed by DHHS. After presenting this, we are requesting four specific actions from DHHS, which are found at the end of the brief.

# Brief to the U.S. Department of Health and Human Services regarding Perivable Birth

*In June of 2017, a pregnant mother named Amanda was experiencing complications and being observed for early labor signs. She and her doctor had already had candid discussions about what she could expect if she were to give birth to her twin sons prematurely. Though early delivery was out of Amanda's control, the doctor informed her that she needed to make it to 22 weeks, 5 days' gestation. Otherwise, no care would be given to her babies. But when this milestone arrived and Amanda went into labor, her doctor was not available, and the attending physician refused treatment despite her doctor's earlier promises. Publicly available video<sup>a</sup> reveals a desperate and powerless mother begging the hospital staff to do something to care for her babies. Meanwhile, several scrubs-clad employees stood bedside, watching as the mother tried to assure her babies that she had tried to save them, even as life ebbed away in her arms.<sup>b</sup>*

*Babies born extremely early, such as Amanda's twins, are referred to as perivable, or more informally as being at "the edge of viability."<sup>1</sup> According to a 2017 Interim Update released jointly by American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal-Fetal Medicine (SMFM), approximately one-half a percent of American births (approx. 20,000 babies per year) fall into this category, which ranges from 20 weeks, 0 days to 25 weeks, 6 days.<sup>2, 3, 4</sup> While babies born in this category account for 40% of American infant deaths, studies throughout the world are reporting encouraging news that survival rates are ever-increasing and are more dependent on medical interventions than previously believed. Additionally, survival is shown to be possible at younger and younger ages, with the youngest perivable baby on record as surviving being 21 weeks, 4 days' gestation.<sup>c, 1</sup>*

## Purpose of This Brief

Sponsors provide this brief to the U.S. Department of Health and Human Services to encourage the Department to investigate possible age-based civil rights violations against live-born babies, to encourage scientific studies on treating extremely premature babies, and to release clear guidance for obstetricians and neonatologists regarding medical standards in the perivable range of gestation.

## Survival of Our Most Vulnerable – A Steadily Increasing Reality

While perivable births are rare, there is a wealth of research to draw from when seeking to understand the survival landscape of extremely premature babies. When examined individually and as a whole, published studies show a consistent, worldwide increase in survival since the turn of the 21<sup>st</sup> century. According to National Institute of Child Health and Human Development's Neonatal Research Network, not only have overall rates of survival of premature babies gone up from rates reported in the early 2000s, but since 2008, the largest increase in survival rates of perivable babies was among 22 to 24-week preemies.<sup>3</sup>

<sup>a</sup> Posted on YouTube by Created Equal: <https://www.createdequal.org/riverside/>

<sup>b</sup> For additional stories like this, see Civil Rights complaints in Appendix A.

<sup>c</sup> For stories of survival after birth at 21 weeks' gestation, see Appendix B.

In its February 16, 2017 issue, *The New England Journal of Medicine* published a study entitled “Survival and Neurodevelopmental Outcomes among Perivable Infants” by Noelle Younge and several of her colleagues in the field. Researchers hailed from several United States universities, including Duke, Stanford, the University of Iowa, and Brown University, among others. Together, they reviewed records from 11 medical centers, uncovering that survival rates among babies born from 22-24 weeks’ gestation had risen by six percentage points (from 30% to 36%) over an 11-year period.<sup>3</sup> This study also found that rates of neurodevelopmental impairment decreased in this same period, resulting in fewer long-lasting disabilities among children born at the perivable stage. A similar study from Japan, published in 2018, reported equally impressive results among babies born between 22- and 24-weeks’ gestation. The researchers found that survival until at least age 3 had increased 9 percentage points over nine years, while rates for 3 out of 4 disabilities they tracked decreased.<sup>5</sup> Comparable results were found in a 2019 study out of Sweden,<sup>6</sup> a 2018 study looking at England’s survival rates,<sup>7</sup> and a 2016 study conducted by researchers at the University of Cologne in Germany.<sup>8</sup>

As the studies above show, the increases in survival are not limited to the “older” perivable babies (those closer to 26 weeks). Though gestational age is a factor in survival, many studies have reported some of the biggest gains in survival rates to be among the 22- and 23-week babies. For example, the 2019 study from Sweden that studied survival-to-one-year rates found the largest increase in perivable survival rates to be among 22-week deliveries, followed closely by 23-week deliveries. This same study even found an increase in the survival of babies under 22 weeks of age, with 2 out of 9 surviving to one year during the 2014-2016 cohort.<sup>6</sup> Again, the studies from England and Germany confirmed these encouraging survival rates for such youngsters. In England, survival rates for 22- and 23-week gestation babies increased over 6% in a 7-year period.<sup>7</sup> The German study (although it did not compare changes in survival rates) tracked births from 2010 to 2014 and found that 66% of the 22-week preemies that were given life-sustaining care survived to discharge.<sup>8</sup> Japanese researchers, in 2013, found that, while the younger babies were still at greater risk of death than slightly older preemies, survival rates for the younger babies rose over time, as well.<sup>9</sup>

### Factors that Lead to Survival

A breadth of research on perivable births shows that many factors affect the odds of survival.

Some of these factors are immutable, such as biological sex, age<sup>d</sup>, weight and plurality. Some other factors are not inherent qualities, but also cannot be easily modified. Where a child is born, for example, plays a large role in probability of survival. Regional differences in provision of life-sustaining care “varies widely among hospitals and developed nations, and this has a significant impact on reported survival rates.”<sup>4, 7</sup>

There are also modifiable factors that must be taken into account when looking at policies regarding the treatment of severely premature babies. These factors fall into two categories: the obstetrical care of the high-risk mother and hospital standards of care regarding initiating or withholding life-sustaining care for her premature baby. Studies demonstrate that the use of antenatal corticosteroids and other preventative measures increase the chance of survival and reduce the rate of disability among

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<sup>d</sup> While GA is a factor for consideration, because it can be so difficult to pinpoint exactly, relying solely on GA proves problematic in treatment decision making.<sup>17</sup>

survivors.<sup>3</sup> Other preventative obstetrical measures include administering magnesium sulfate for neuroprotection, tocolytic therapy, antibiotics for latency after premature rupture of the membranes and group B streptococci prophylaxis.<sup>2</sup> This type of care requires collaboration between involved specialists. The utilization of such collaboration is a modifiable factor that could lead to higher survival rates.<sup>10</sup>

When an extremely premature baby is born, its survival is dependent on the hospital's standard of care regarding initiating or withholding life-sustaining care. This is an extremely important modifiable factor. If a 22-week baby given life-sustaining care immediately at birth survives for 7 days, she has three times the chance that she will survive till discharge (from 15% to 45%).<sup>4</sup>

Offering immediate life-sustaining treatment to preemies born at 22 weeks is the largest modifiable factor affecting survival. Every baby who is denied life-saving care at this age will certainly die, usually within 3 hours of birth.<sup>11</sup> When given treatment, however, the baby's likelihood of survival increases significantly compared to any other factor, immutable or modified. Though gestational age and birthweight can be helpful metrics to neonatologists in the clinical environment, these factors are not fool-proof and can result in withholding life-sustaining care from babies that otherwise would have survived.<sup>12</sup> Providing life-sustaining care as the default standard (default-treatment) yields remarkably better results than attempting to assess first and treat later.<sup>12</sup> For example, the University of Iowa defaults to immediately initiating active, life-sustaining treatment for 22-week babies and has long had a survival rate of over 60%.<sup>10,13</sup> The national average is only 38%.<sup>14</sup>

As discussed, the choice to provide or withhold life-sustaining care is a major modifiable factor because, despite the aforementioned increase in infant survival, some doctors and hospitals still prefer a default strategy to not actively treat perivable neonates (default-palliative). Dr. Joseph Kaempf, a neonatologist who is also a prolific writer on medical treatment options for premature babies, prefers this strategy. In 2016, Dr. Kaempf's clinic saw only a 21% survival rate for babies born at 23-weeks' gestation, far below the national average of 38%, despite his presumed expertise in this area.<sup>14</sup> As recently as 2017, Dr. Kaempf and his colleagues maintained a clinic-wide policy that refused treatment for 22-week babies. This refusal to treat was based only on gestational age, without parental input,<sup>15</sup> and despite substantial evidence that such policies are harmful to overall survival and disability rates.

In 2018, a comparative ten-year study from Sweden and the US found that when the studied facilities defaulted to treatment, a significantly higher percentage of babies survived than when a facility did not. They noted that in the default-treatment city of Uppsala, Sweden, the "go-home rate" was 53% while the default-palliative city of Columbus, Ohio, saw only 8% of perivable infant survive to discharge.<sup>10</sup> Moreover, the study also found that default-treatment leads to a much lower rate of moderate-to-severe impairments. The Swedish NICU had a low overall rate of moderate-to-severe long-term impairment of 25%, while its rate of no long-term impairment was 55%. Conversely, the Ohio NICU had a 100% moderate-to-severe impairment rate.<sup>10</sup> Even more encouraging is a 2020 study from the University of Iowa showing a survival-to-discharge rate of 78% (for 22- to 23-week babies), while 64% of survivor had either no disability or only mild long-term disability noted at 64%.<sup>13</sup>

## Current State of Treatment and Accepted Guidelines

Still, there are doctors who inform pleading mothers who desire to see their preemie children given a chance to live that they will not intervene. While a 2016 study from the University of Cologne (Germany)

found 95% of 23-week babies and 62% of 22-week babies received active life-sustaining care,<sup>8</sup> this is rarely the case in America.

Several American health organizations offer guidelines to help physicians determine what care is appropriate for premature babies, based upon their gestational age and other early neonatal assessments.<sup>12</sup> Overall, the guidelines agree that while births at 22 weeks and shortly after can effect a precarious situation for all involved, consultation and joint decision making with informed parents is always preferable over plans made by the physician alone. Generally speaking, the most up-to-date guidelines also favor active resuscitative care when the family requests it. For example, the American Academy of Pediatrics (AAP) and the American Heart Association (AHA) have stated that there are only two situations in which intensive measures should be withheld: (1) when the physician believes there is absolutely no chance of survival and (2) when there is agreement between parents and medical caregivers that intensive measures will not improve the chance of survival. Outside of these two situations, the physician should always begin resuscitation “pending further discussions” with the parents, even in cases where the parents’ views are unknown or uncertain.<sup>16</sup>

Similarly, a consensus statement from the American College of Obstetricians and Gynecologists (ACOG) and Society for Maternal-Fetal Medicine recommends neonatal resuscitation should, at the least, be considered in consultation with parents for all births between 22 weeks, 0 days’ through 23 weeks, 6 days’ gestation. ACOG’s statement also points out the importance of relying on factors beyond simple gestational age measurements.<sup>2</sup>

Guidelines issued in 2019 by Yale’s Chief of Neonatal-Perinatal Medicine, Dr. Mark Mercurio, recommend that resuscitation should be “offered to parents if there is at least a small chance of survival based on available information.” It will then be provided to the baby “if requested by informed parents.” The foundational belief of these guidelines is that extremely preterm babies should be cared for “based on the available evidence, and the values and preferences of fully-informed parents.”<sup>17</sup>

## Why Aren’t All Doctors Providing Active Treatment?

Since studies are showing increased survival rates and the most recently published guidelines for resuscitation recommend offering resuscitation for babies newly born at 22 weeks’ gestation, the obvious question must be raised: why are some perivable babies being denied treatment despite the tearful and urgent pleas for care made by their mothers? Upon investigation, it becomes evident that “[e]ven though medical indications are traditionally considered as a purely medical matter ... physicians’ personal values may influence how they interpret medical indications – a phenomenon called value-impregnated factual judgements.”<sup>18</sup> The unfortunate reality is that many doctors prioritize the following factors over both parental wishes and even the most up-to-date research.

### Discrimination – Perpetuating negative attitudes about quality of life and disability

One factor is the tendency for some studies and practitioners to create “quality of life” scenarios by conflating statistics on neonatal death and statistics on the probability of survival with disabilities.<sup>19</sup> For example, one recent study reported encouraging findings about both an increase in survival rates and a decrease in longer term disability. However, even with these promising results, the authors unnecessarily group their findings into “negative” outcomes, treating death and disability as equivalent.

For example, the study reported, “The incidence of death or neurodevelopmental impairments (NDIs) at a chronological age of 36–42 months was 80% of those born at 22 weeks and 64% at 23 weeks.”<sup>5</sup> This report does not tell us how many of that 80% survived and lived life as a loved and cared-for child, regardless of disabilities, nor does it even indicate the degree of disability.

Other authors are more transparent about their view that disability equals misery. In his column entitled “It is not ethical to save an infant’s life just because we can, without due regard to outcome,” bioethicist Gert Helgesson argues that doctors have an ethical duty to consider quality of life when a child could have any disability at all, stating that some lives are of “questionable value.”<sup>20</sup> Though he acknowledges that the gap between *disability-free* and *not worth living* can be considerable, Helgesson also warns doctors not to approach the situation from the standpoint that every life is worth living. Significantly, Helgesson does eventually conclude that, for cases that fall in between the clearly futile and the clearly warranted healthcare, parents should ultimately make the choice for their children. Still, this suggestion is buried within the greater framework of the piece, and the reader comes away with the overwhelming message that some lives would not be worth living and should not be saved.

The sad reality is that this attitude translates to how doctors approach patient consultations. Dr. Patrick Marmion tells of a situation he witnessed where a physician told parents that their preemie had a 89% risk of either dying or being disabled. Dr. Marmion disagrees with the idea of combining these two outcomes and states that physicians should instead tell the survival rate (40%) and then address the additional likelihood of being disability-free (67%).<sup>14</sup> This change in focus would more closely match how physicians discuss such statistics in the adult ICU, where similar percentages would result in treatment by default, while palliative care would rarely even be offered during the first days after admission.<sup>14</sup>

When doctors rely on published death/disability statistics to counsel parents through shared decision making, they are creating a snapshot of misery for a child’s future. While identifying “at-risk” babies is important in treatment decision making, lumping disability as a negative outcome on par with death takes the focus away from other more encouraging findings that “[m]any children will catch up to their peers by school age.”<sup>3</sup>

Adding more nuance to the analysis, the 2017 Interim Update on Perivable Birth, released by ACOG, cites a study out of England that found gestational age at birth has a very complicated relationship to overall disability rates. Though rates of disability among 22- to 23-week babies decreased as they developed (45% at age 30 months to 40-43% by age 4-8 years), the rate of disability among 25-week babies rose for the same timeframe (from 17% at age 30 months to 24% at age 4-8).<sup>2</sup> Thus, childhood measures of disability may fluctuate throughout the course of a child’s growth. In the end, the so-called “quality of life” related to one’s medical health tends to even out between low birth-weight babies and regular-weight peers by young adulthood.<sup>14</sup> But these details are unlikely to be teased out in discussions with parents if death and disability are presented as a single, ominous outcome.

In addition to presenting an incomplete picture to parents, doctors’ own views of what is considered futile can be influenced by the habitual combination of disability with death. Where doctors see a high rate of death/disability among perivable babies, they may automatically conclude to themselves – and thus counsel the parents – that care is “futile.” This may lead the parents to

believe that there is no chance of the treatments working to save the life of their child, when in reality there are many instances of babies at 22 weeks surviving.<sup>10</sup> Still, physicians' decisions and recommendations may be based on the belief that saving a baby to live a life with disability is tantamount to futility.<sup>14</sup>

Ironically, studies show that the rates of disability directly correlate to the rates of active life-sustaining treatment given. For example, the previously referenced 2018 study comparing results from one NICU in Sweden and one NICU in Ohio found a difference in impairment rate of long-term outcome. Recall the above-referenced studies: the Swedish NICU defaulted to strategy that provided life-sustaining care and saw a rate of moderate to severe impairment of 25%, which was dwarfed by its rate of no long-term impairment (55%).<sup>e</sup> The Ohio NICU, meanwhile, had a strategy that defaulted to withhold initiating life-sustaining care and reported that 100% of surviving babies experienced moderate-to-severe impairment.<sup>10</sup>

It is important for HHS to deliver a strong statement that age and ability-related discrimination will not be tolerated in American hospitals.

### Focus on Costs – Using the bottom line to wash hands of duty

In discussions related to “futile” care, doctors may also use the word as code to mean that the survival of the baby is not worth the cost of the treatment.<sup>10</sup> Though various studies have shown that costs for NICU treatments are one-twentieth to one-tenth the costs of treatments for adult ICU patients,<sup>f,14</sup> some researchers and doctors advocate for still more studies on very young babies before they are willing to determine that the quality of life obtained is worth the treatment costs.

Neonatologist and clinical researcher at Sainte Justine University in Montreal, Keith Barrington argues that this very “quality of life versus cost” attitude can interfere with a doctor’s decision making and points out the importance of having a positive attitude from the start of treatment, believing that it is possible for the child to both survive and thrive.<sup>10</sup> Often physician decisions and recommendations are based on personal beliefs about futility, quality of life, and costs of treatment coming from a status quo mindset, rather than a progressive forward-thinking approach—an approach that is essential when dealing with perivable babies where outcomes are so dependent on the development of new technologies.<sup>14</sup> A static belief system based on treatment costs is less likely to yield the results for which parents and medical professionals alike are hoping simply because the negative outcome has been determined before the doctor even gave the treatment a chance.

HHS can help medical practitioners stay informed on the most up-to-date treatment and on the facts about cost of treatment by funding studies and awarding training program grants for medical professionals and administrators to instruct on ethical decision making.

<sup>e</sup> A wider study of Swedish outcomes showed significant change improvement in those rates of over 12 years. In that study, survival rates rose 10%, while survival without neonatal morbidity rose almost 19%.<sup>6</sup>

<sup>f</sup> when adjusted for the future life expectancy

### Regional Practices – A child’s zip code shouldn’t determine whether she lives or dies

As discussed above, when doctors live in a location that defaults to low treatment rates, they are likely to also see lower survival rates of the babies who are given treatment. This may influence their future recommendations and decisions on whether to offer certain care. Studies of Swedish practices consistently show they have both high rates of treatment and high rates of survival of preterm babies when compared to other European countries.<sup>10, 6</sup> France, for example, has an almost 100% death rate for babies born at 23 weeks’ gestation. Unfortunately, a 2017 study found that “country of birth has a large impact on the probability of survival” with survival rates spanning 0-37% for 22-week births among various European countries.<sup>4</sup> Even Sweden, with its high rates of success in treating its youngest born residents, still sees variance between locales because some doctors provide treatment to preterm babies based upon their views regarding treatment rather than on physician ability or the resources available.<sup>18</sup>

American medical facilities likewise see varied rates of survival based on both geography and even the specific facility to which a mother is admitted. While generally speaking, the availability of a NICU in a geographical area increases chances of survival, when NICUs become more commonplace, each unit may see fewer individual cases of perivable births each year and, thus, have less experience in successfully treating these babies.<sup>4</sup> This can then perpetuate the myth that active treatment is “futile.” Still, evidence shows that facilities within close proximity of each other can work toward successful survival rates when high-quality specialized treatment is offered at the regional level.<sup>2, 4</sup> However, this cooperation also requires hospitals have policies and procedures in place to facilitate timely transfers to regional Level III or IV NICUs.<sup>2</sup>

Fortunately, we know that when a child is born at an American Level III and IV NICU, physicians can attain astounding results if they approach care from a default-treatment strategy. Research practitioners at the University of Iowa recently published their impressive results in the February 2020 volume of *The Journal of Pediatrics*. Between 2006 to 2015, only 7 out of the 255 perivable babies born at the University of Iowa Stead Family Children’s Hospital were not given life-sustaining care. The reasons for this were congenital anomaly, death in delivery room, or parental request for palliation. Of the 248 remaining babies, 214 survived to discharge and went home with their families. In the journal article, University of Iowa physicians directly credit their default-treatment strategy.<sup>13</sup>

The University of Iowa is leading the way in successful medical treatment of perivable patients, leading many Americans to ask whether the term *perivable* still applies to 22-weeks’ gestation babies. After all, with such high survival rates, it could be time to acknowledge that 22 weeks, in fact, is solidly in the *viable* category. However, there is still a need for more guidance so that the medical community at large can become informed, trained, and experienced in these exciting advances.

HHS is in a prime position to award grants for continuing education programs for medical professionals. HHS should also issue guidance encouraging localities to work together to establish specialized care facilities for at-risk pregnancies. Additionally, HHS should prepare sample policies and procedures to assist hospitals in implementing clear and transparent transfer plans.

Rugged Individualism – Saving lives is a team effort too often approached alone. There are two general areas where teamwork can also play a part in a physician’s decision to not offer medical treatment for an extremely premature baby.

### **Isolated Specialists**

The first area is the relationship between various specialists who are or will be involved in the delivery. Unsurprisingly, a 2015 study found that obstetricians and neonatologists often focus on different topics in their consultations with parents. For example, obstetricians tend to discuss things like maternal health risks and whether a cesarean would be appropriate, while neonatologists focus on post-birth complications and treatment options for the baby. The study also found, unfortunately, that some essential topics were left undiscussed altogether. For example, neither specialist took ownership of the issue of whether to use antenatal steroids and instead directed their patients to speak with the other specialist.<sup>21</sup>

Because of this difference in consultation focus and the reluctance physicians showed to take ownership of the steroid discussion, mothers facing difficult pregnancies may find themselves in the middle of a communication breakdown between two of their most important team members. To avoid this breakdown, the obstetric and neonatology teams ought to either consult simultaneously, or at least coordinate to keep each other informed of what was discussed with the patient. This would avoid both providing her with contradictory information and completely omitting information – the last thing a woman in a high-risk pregnancy needs.<sup>2,10</sup>

### **Isolated Team Members**

Another area where lack of physician teamwork can have a negative effect on neonatal care occurs when the physicians who consulted with the mother before early labor are unavailable at the time of early labor. At this time, the on-call or attending physician will need to step in and make decisions of treatment despite having limited knowledge of the pregnancy history or any previous conversations surrounding care. This can result in a deviation away from carefully discussed plans that were agreed upon by a mother and her primary physician. In its 2016 Interim Update, ACOG recommends that delivery units have established systems in place to guard against these off-the-cuff treatment plans. Such systems should address both the importance of respecting plans created previously and the protocols for handling “conflicts of conscience that may arise,” such as situations where the on-call physician is unwilling to treat a perivable baby, despite a plan being already in place from the primary physician to do so.<sup>2</sup>

HHS can offer guidance and funding for training to medical professionals for effective pre-birth and post-birth family consultation that focus on the holistic person of both mother and child. HHS should also prepare sample policies and procedures to assist hospitals in implementing clear and transparent default-to-treatment plans.

When viewed overall, these factors show that physicians may not be utilizing current research or keeping parental goals as a top priority in deciding which treatment options to offer. As ACOG recommends, parental goals for medical care, such as “optimizing survival or minimizing pain and suffering,” should always be a primary factor in the care plan development.<sup>2</sup> However, not every

physician will be up to date on every study, nor will they all have experience treating (whether successfully or unsuccessfully) perivable babies.

This makes it of primary importance that an entity like HHS, which has the influence and resources to assist physicians in helping parents make the best decisions for their babies both before and after birth, step in to assist them. With this in mind, we submit this brief to the U.S. Department of Health and Human Services and request the action steps in the following Call to Action.

## Sources

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<sup>17</sup> Mercurio M, Martin R, Kim M. Perivable birth (Limit of viability). *UpToDate.* 2019 Jan 17; accessed 2019 May 11. <https://www.uptodate.com/contents/perivable-birth-limit-of-viability>

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<sup>19</sup> Barrington, Keith. Is the glass 81% full or 19% empty? *Neonatal Research Blog.* 2012 Dec. 17, accessed 2020 Mar. 4. <https://neonatalresearch.org/2012/12/17/is-the-glass-81-full-or-19-empty/>

<sup>20</sup> Helgesson, Gert. It is not ethical to save an infant's life just because we can, without due regard to outcome. *Acta Paediatr.* 2018 Feb;107(2):194-195.

<sup>21</sup> Tucker Edmonds B, McKenzie F, et. al. Comparing Obstetricians' and Neonatologists' Approaches to Perivable Counseling. *J Perinatol.* 2015 May;35(5):344-8.

## What DHHS Can Do

Sponsors of this brief respectfully request that the U.S. Department of Health and Human Services take the following actions to support parents facing extremely pre-term births:

- 1) Investigate the attached Civil Rights complaints from parents whose babies were discriminatorily denied medical treatment based on age and/or disability. See Appendix A.
- 2) Earmark funding for studies and training programs for physicians intended to deepen understanding and enhance utilization of the most effective treatments for our youngest born members of society.
- 3) Issue an official position that babies born at 22 weeks' gestation are presumed viable in the absence of significant and situation-specific factors that clearly demonstrate otherwise.
- 4) Issue clear regulations or guidance to obstetricians, neonatologists, labor and delivery unit administrators, and other involved medical professionals on how to best care for perivable babies, including guidance that advises medical professionals to:
  - a) Establish a transparent, facility-wide, default-treatment policy for perivable babies beginning at 22 weeks' gestation.
    - i) Hospitals should educate physicians with admitting privileges on the correlation between default-treatment and better overall survival rates.
    - ii) Default-treatment policies can be balanced by continuous reassessment (with follow-up family meetings) as the clinical situation develops.
    - iii) Policies should include visible signs explaining the policy, as well as signed informed consent forms in the event that parents opt out of active treatment.
    - iv) Policies should provide physicians with a clear and non-judgmental process to recuse themselves from perivable cases in the event their consciences direct them away from default-treatment strategies.
  - b) Prioritize parents' understanding of their child's medical needs and options for treatment
    - i) Conduct joint antenatal and postnatal family meetings with specialists and additional on-call team members to ensure a comprehensive and clearly understood plan, including the discussion of steroid use.
    - ii) Separate different outcomes when communicating risk of death and chances of survival with or without disability.
    - iii) Engage in shared decision making with parents, giving treatment options that align with parents' goals for their children and support parents' values.
    - iv) Require parent signature on informed consent forms if parents choose palliative comfort care, including DNRs.
  - c) Institute admission and transfer policies and procedures to ensure that mothers are at the most appropriate facility for their babies' treatment needs.
  - d) Establish protocols for more compassionate comfort care, emphasizing the legal personhood of the baby and addressing the grief of the parents.
    - i) Protocols for comfort care should highlight the fact that all babies who are born alive are deserving of care and are defined as persons by law.
    - ii) Grief counseling should address parental distress stemming from both the informed decision to withhold or withdraw care and the loss of the valued life of their baby.

# Appendix A

This Appendix contains OCR Discrimination Complaints for the following children who were born prematurely and denied life-sustaining care without regard for their parents' wishes.

**Complaints have not been published  
to protect patient confidentiality.**

# 15 Stories Of Premature Babies That Survived Against The Odds

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BY RAJENDER BHATIA  
NOV 12, 2016

<https://www.babygaga.com/15-stories-of-premature-babies-that-survived-against-the-odds/>

#11 Sharing The Record Of World's Most Premature Baby - James Elgin Gill (1987)



James Elgin Gill is the oldest known most premature baby who was born in 1987 in Ottawa, Canada, at 21 weeks. He was the most premature baby to survive at the time. The doctors had no hope of his survival and they said even if he lives he will lead a life struggling with disabilities.

However, James was last known to have gone to college in 2006. He is really famous for battling the odds and his example of survival time and again reminds the medical community to give a chance to preemies and resuscitate the babies born before 23 weeks.

James survived in times when the medical facilities were not as advanced as today. Medical practices have evolved and changed in time. Revolutionary breakthroughs in other medical areas have given life to millions around the world. Then, why not preemies?

With examples like James and Frieda, many believe it is time that authorities revise the viability of a premature baby and give support to hospitals to develop expertise in saving little ones coming out early.

## 'World's most premature baby' to leave hospital

1:24PM BST 23 Apr 2011

<https://www.telegraph.co.uk/news/worldnews/europe/germany/8469561/Worlds-most-premature-baby-to-leave-hospital.html>

A German woman has given birth to a one-pound baby after only 21 weeks and five days of pregnancy, making it one of the world's most premature babies to survive.

The baby, named Frieda, was born on November 7 measuring 11 inches and weighing only one pound.

She is thought to be one of the world's most premature babies to live.

The previous record was thought to be held by Canadian James Gill, who was also born 21 weeks and five days early, in 1987.

In July, Britain's most premature baby to survive, Amelia Hope Burden, was born before after 23 weeks and two days.

Five and a half months later, Frieda is finally fit to leave the clinic in Fulda, western Germany, in the next few days, now weighing 7.7 pounds.

The German newspaper Bild reported that her twin brother Kilian died a few days after being born.

A doctor on duty said that "there is no foreseeable risk of after-effects for the moment" and that the little girl "should develop normally like any other child."

Professor Reinald Repp, director of the paediatric clinic, told the newspaper that her survival was "a miracle" because generally babies born before 22 weeks have no chance because their lungs, heart and brain are not sufficiently developed.

"Frieda was kept in a completely sterile environment, with her breathing assisted and fed through her navel," he said.

Any baby born before eight months of pregnancy is considered premature.

Very premature babies (less than 32 weeks) are considered at high risk of suffering developmental problems.

## The most premature surviving baby was born at 21 weeks

Nov. 9, 2017, 9:48 AM PST / Updated Nov. 21, 2018, 9:12 AM PST

<https://www.today.com/health/born-21-weeks-she-may-be-most-premature-surviving-baby-t118610>

The baby girl weighed less than a pound when she was born just 21 weeks into Courtney Stensrud's pregnancy. Infants that tiny and undeveloped aren't expected to survive outside the womb, but her mother insisted that she be resuscitated.

Lyla — who is now 4 — appears to have made medical history.



Lyla was 3 weeks old in this picture. "When she was born her eyes were still fused shut. This photo was from the day her eyes opened," her mom Courtney Stensrud said. Her wedding ring is on the baby's right arm. Courtesy Courtney Stensrud

Her doctors believe the Texas girl is the most premature surviving baby ever reported. Her case means they can no longer say death is certain for babies delivered at 21 weeks' gestation, "though it remains highly probable," wrote Dr. Kaashif Ahmad, a MEDNAX-affiliated neonatologist at the Pediatric Medical Group of San Antonio, Texas, last year in the journal Pediatrics.

"I feel blessed that we were given this little miracle baby," Stensrud told TODAY when Lyla's story first went public in 2017.

When TODAY caught up with her on Thanksgiving Eve 2018, she had a lot to be thankful for. Lyla is a little behind on speech, but she's otherwise "doing really well" and doesn't have any medical issues or disabilities, her mom said. The girl will soon return to preschool and recently attended a NICU reunion at Methodist Children's Hospital.



Stensrud has started a blog to tell her daughter's story and reach other families who may be going through a similar situation.

Doctors can't predict Lyla's future, but they have every reason to be hopeful for her continued long-term good health, Ahmad noted.

"Lyla is a beautiful... wonderful little girl," he said. "Lyla not only fought and survived to make it home, but is thriving today. Knowing her over the past four years has been an extraordinary journey."

# Kansas City baby defying the odds after being born at 21 weeks & six days

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Posted: 4:59 AM, Nov 17, 2017 Updated: 7:13 AM, Nov 17, 2017

<https://www.kshb.com/news/local-news/kansas-city-baby-defying-the-odds-after-being-born-at-21-weeks-six-days>

*KANSAS CITY, Mo.* — Premature birth is the number one killer of babies, and for the first time in eight years, March of Dimes says more children are being born prematurely.

Walk into the NICU at St. Luke's and you'll find little Eliora.

She is nearly eight pounds, and her parents say she is a miracle.

"21 weeks and 6 days. We thought this was it, you know, we were going to lose our sweetie," said Robin Schneider.

Doctors at St. Luke's agree, saying Ellie's journey has been amazing.

"I think that her journey has been remarkable," said Dr. Inny Levezzi. "She's had a relatively good outcome so far and you know, I think that that's something to celebrate for her."

It sounds cliche, but it's been a long road for Joel and Robin Schneider.

"She was 14 ounces, which is just a little bigger than a can of Coke," said Robin Schneider.

Ellie only spent two more days in the womb than the most premature baby on record.

The couple already has a son but as they welcomed their early arrival, they waited four months to hear her cry.

"Just hearing a tiny cry from her... brought tears to our eyes. It had been months and months just waiting to just hear our baby's voice for the first time," said Joel Schneider.



*Photo of the Schneider family courtesy Joel Schneider*

As she continues to beat the odds, if Ellie could talk she'd say I'm not going down without a fight.

"The fact that she's alive and has as few complications as she does is a miracle. There's no other way around it. Whether or not you believe in God -- it's a miracle. She should not be here... and she needs to know that. That she has a special calling on her life," said Robin Schneider.

The Schneiders have a GoFundMe page for help with medical costs.

Earlier this year, St. Luke's created a program specifically for babies born 24 weeks or earlier. So far, they've had an 86 percent survival rate.

# J.R. Smith Brings Prematurely Born Baby Girl Home From NICU

BY CORINNE HELLER | Wed., May. 24, 2017 9:22 AM

<https://www.eonline.com/news/856799/j-r-smith-brings-prematurely-born-baby-girl-dakota-home-from-hospital-nicu>



Instagram

Baby Kota is home!

This past January, Cleveland Cavaliers player J.R. Smith's wife Jewel Harris gave birth at Hillcrest Hospital in Mayfield Heights, Ohio to their daughter, Dakota, five months early at 21 gestational weeks. The baby weighed one pound—at least five times less than the normal birth weight, making her a micro preemie—and was rushed to the NICU. She was released from the hospital Tuesday, weighing a healthy 7 pounds and 5 ounces.

"We Walked In Together We Walked Out Together!!" Smith wrote on Instagram, alongside a heartwarming photo collage of him and his wife leaving with their baby in a stroller. "Thank you so much to our extended family at the #NICU You all are truly the WORLDS GREATEST! @jewey808 back to #TeamNoSleep #KotasHome."



Instagram

The child joins big sisters Demi and Peyton.

Smith posted on Wednesday a photo of the baby sleeping on his bare chest with Demi cuddled up, staring at her new sister. Dakota is wearing an oxygen tube. In the weeks following birth, premature babies often have difficulty breathing.

On Instagram, the NBA player has chronicled Dakota's progress in the NICU.

"Today is one of the greatest days of my life. Today I get to hold my youngest for the first time! GOD is GREAT! #DakotaStrong," he wrote in February.

# Extreme preemie born at 21 weeks young at Emory Decatur Hospital

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By George Franco Published December 26, 2019

<https://www.fox29.com/news/extreme-preemie-born-at-21-weeks-young-at-emory-decatur-hospital>

**DECATUR, Ga.** - A Jonesboro mother and father are hoping for the best after the birth of what they describe as a Christmastime miracle, a baby boy born extremely prematurely. Jemarius Jachin Harbor is at the Neonatal Intensive Care Unit at Emory Decatur Hospital against some very long odds. He emerged into the world at only 21 weeks young, weighing only 13 ounces, smaller than the size of a hand on Friday December 20.

"I had just 21 weeks at 12 o'clock, 12:12 I had him. He's actually has a fighting chance, that's my miracle baby," said Jessica McPherson, his mother.

Jessica McPherson told FOX 5 News when she was in labor she and her fiancé Jemarius Harbor Senior asked the doctor and staff at Emory Decatur Hospital to do all they could to save Jemarius Junior.

"We looked at each other in the eye and I told him just give it a try. I just want you to try as long as you try that's all that matters to me, don't just up and say that you can't do it. Just 'cause you haven't done it doesn't mean it can't be done," said McPherson.

Gina Phillips, Director of Medical Services, with Pregnancy Aid Clinics, which helps at risk mothers said premature babies born at 23 weeks are considered the limit of viability.

"At 22 weeks some are surviving but 21 weeks is a very rarity it would be short of a miracle," said Phillips.



She said the typical survival rate for a baby born at 21 weeks is less than four percent. Phillips told FOX 5 News at 21 weeks Jemarius' lungs are not quite ready to function outside of the uterus and that he is at a high risk for infection.

She remains optimistic because in medicine and technology have improved survival chances of extreme preemie babies. "They did have a 21-week-old and four-day baby girl survived in Europe and without any complications, she's several years old now," said Phillips. Which is great news for the parents of Jemarius.

"If this child can make it maybe my child can make it as well," said McPherson.



She said she lost two previous preemies at 22 weeks each. Holding the hospital blanket Jemarius was first wrapped in his parents are placing their hopes on his fight for life, his doctors and their faith. "You know there are going to be good days and going to be bad days because he is so small but as long as we stay positive that's all that matters," said McPherson.

She said she expects her newborn son to leave Emory Decatur Hospital in March or April which would be the time of full term.



FOX 5 News did not hear back from representatives with Emory Hospital Decatur to check the claim Jemarius parents made that he is the youngest preemie born at that hospital system.

# Update on Jemarius Harbor

Sunday, April 12, 2020 9:02 AM

<https://www.facebook.com/amomentwithkailor/photos/a.2217980658512113/2496243650685811/?type=3&theater>



A Moment with Kailor  
Like This Page · April 6 ·

21 weeker update

Jemarius was born at 21 weeks 0 days.

Weighing 13 ounces at birth.

He's now 3 lb 8 ounces!

He is NOW 3 months old.

He is currently the youngest survivor in the entire world.

He's at Emory in Decatur, Ga.

760

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