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A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

## NEWBORN CARE AND “LETHAL” PRENATAL DIAGNOSES

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One of the most difficult challenges for parents experiencing a prenatal diagnosis is the often traumatizing and inaccurate attachment of lethal language to the baby alive in the womb. In our work with the Catholic nonprofit organization Be Not Afraid for almost twelve years, we have had the privilege of supporting over one hundred seventy families carrying to term following a prenatal diagnosis through comprehensive case management, referrals, and practical information. Most of the babies welcomed in our service were infants for whom medical providers offered no hope at diagnosis, but every year survivors exceed all medical expectations.

A significant proportion of our families deal with a prenatal diagnosis of trisomy 13 or trisomy 18, genetic anomalies in which there are three copies of the thirteenth or eighteenth chromosome, instead of the typical two, respectively.<sup>1</sup> In the more prevalent versions of the syndromes, every cell in the body has the triple chromosome. Individuals with trisomy 13 and 18 have significant intellectual disabilities. In addition, the conditions often include structural anomalies that can affect the likelihood of survival, so they are properly classified as life-limiting disorders. While some babies with trisomy 13 and 18 will die, not all do, yet at diagnosis parents are seldom offered any indication that anything other than imminent death is possible.

For this reason we have always encouraged parents to prepare a birth plan and a newborn care plan that anticipate not only death, but more importantly (particularly for Catholic parents), life. Our advocacy not only helps parents to secure basic care for their infants at birth, but also encourages them to consider fully treatment options that may be appropriate for their child after birth no matter the diagnosis. Based on our determination to provide even more robust support and guidance for care of the

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living infant, in 2019 we published “Ethical Care of Infants with a Life-Limiting Prenatal Diagnosis Based on Catholic Teaching,” which asserts the moral and medical necessity of treating babies with so-called lethal prenatal diagnoses just like every other baby.

### Effect on Obstetric and Newborn Care

Recent research indicates that lethal language such as “fatal fetal anomaly,” “lethal or terminal prenatal diagnosis,” and “incompatible with life” is used so that parents have an easier time coming to terms with the decision to abort their child, not because doctors can predict with any certainty whether a baby will live or die at birth. Similarly, for those who carry to term, the decision to limit care options at birth may be more easily made if parents believe there is no hope for their baby to survive.

Lethal language, once attached at diagnosis, will often be used to determine whether parents carrying to term have access to fetal monitoring during labor and delivery or a cesarean section if there is fetal distress. The care given to babies at birth may also be limited.<sup>2</sup> To this extent, lethal language has potential ethical implications, as it may trigger different obstetric management for women who carry to term. In addition, the lethal language often results in perinatal palliative care services being presented as the default course of action for the baby, sometimes without parents being informed that other possibilities exist.

Kristen Buffkin’s experience when her daughter Emmy was prenatally diagnosed with trisomy 18 offers dramatic insight into the effect of lethal language: “The doctors offered almost no hope at diagnosis. We were told that this diagnosis was not compatible with life and that our baby would likely die in utero over the next few weeks and if she made it full term, she would likely die during childbirth. Abortion was presented to us as a treatment option. Either terminate this life that was already doomed to die or allow it to die on its own. These were our two choices.”<sup>3</sup>

Kristen and her husband Jason declined termination and ultimately were referred to a palliative care program when Emmy was still alive at thirty seven-weeks’ gestation. Even then doctors offered little hope that she would survive birth, and the couple was advised to forgo fetal monitoring during labor. Kristen still struggles with that decision: “These medical professionals make you start believing that they know what is going to happen, like they knew for sure she wasn’t going to make it. I loved my daughter more than anything, but I agreed to not monitor her heart during birth. I hate that I made that decision, but everyone made it sound like it was the right thing to do.”

Despite the negative prognoses, Emmy was born alive at forty two-weeks' gestation on July 26, 2016, weighing 5 lbs., 5 oz. She was discharged at twenty-four hours with a nasogastric tube to support feeding and an oxygen nasal cannula. She lived for one hundred eighteen days. The doctors were wrong.

### Prenatal Prognoses Are Less Certain Than Presumed

While parents believe the assertion of lethality to be clinically significant, fatal terminology conveys a false impression that a prognosis can be made with certainty prenatally.<sup>4</sup> Not only is that untrue, but studies have found that when offered the same medical care as other babies at birth, newborns with conditions like trisomy 13 and 18 can do better than anticipated.<sup>5</sup> A 2016 study reported that the one-year survival rate jumped to 69–71 percent among infants who had a variety of indicated surgical interventions.<sup>6</sup> In 2017 researchers at Stanford University and the University of Arkansas found that the survival rate almost doubled among babies with trisomy 18 if they received heart surgery.<sup>7</sup> Yet parents are still routinely told that these genetic syndromes are lethal, and that basic care and treatment for secondary conditions is futile. Indeed, the diagnosis itself can affect the prognosis and become a self-fulfilling prophecy, as noted by neonatologist Martin McCaffrey: “As regards predicting a condition is lethal, potentially lifesaving treatments are withheld. As a result, patients who might have survived will then die, perpetuating the belief that the condition is lethal.”<sup>8</sup>

John Lantos, the director of the Bioethics Center at Children’s Mercy Hospital in Kansas City, Missouri, and a professor of pediatrics at University of Missouri–Kansas City School of Medicine, explains, “Many clinicians object to life-sustaining treatment of infants with trisomy 13 and 18. These views are based on 2 ideas. First, that these trisomies are uniformly fatal or lethal conditions. Second, that the burdens of treatment under these circumstances outweigh the benefits. *These views are no longer tenable.* Many infants with these trisomies survive for years. Many parents report that infants with trisomies have an acceptable quality of life and are valued members of families.”<sup>9</sup>

### Variation in Outcomes for Newborns

Research shows outcomes for babies with trisomy 13 and 18 vary by both the state of residence and whether the diagnosis is made prenatally or after birth. This variability in survivals forces an examination of the factors that might contribute to such inconsistency in outcomes.

A 2015 study published in the *American Journal of Medical Genetics* indicates that regional differences in care may produce differences in outcome. This study compared data on the survival rates of infants with trisomy 13 and 18 from nine states and discovered significant variation. Notably, the probability of survival to one year was twice as high for infants with trisomy 18 born in Georgia (24.6 percent) as it was for babies born in Arizona (9.3 percent), Illinois

(10.2 percent), and North Carolina (9.8 percent). The study authors observed, “It is possible that local differences in the aggressiveness of medical management of infants with T13 or T18 may contribute to the variation in survival among states.”<sup>10</sup> Our experiences in the field support that finding. For instance, in Georgia infants with trisomy 13 and 18 are more likely to be evaluated as candidates for heart surgeries than are infants in nearby North Carolina, where no institutions routinely perform surgeries on such patients.

Similarly, a 2016 study also published in the *American Journal of Medical Genetics* found that survival was related to whether a baby was diagnosed with trisomy 13 or trisomy 18 prenatally or at birth.<sup>11</sup> The babies diagnosed prenatally were significantly more likely to die shortly after birth than were those children diagnosed in the postnatal period. It should be noted that 100 percent of the parents with a prenatal diagnosis were encouraged to limit care at birth, and that the infants with trisomy 13 and 18 born without a prenatal diagnosis had the benefit of being treated like any other infant until that diagnosis was made. Thirty-six percent of the children diagnosed prenatally died in the first twenty-four hours, whereas only 1 percent of the children diagnosed postnatally died in the same timeframe. If presuming lethality, one could imagine that a larger proportion of the postnatally diagnosed infants would die in the weeks to come as they were removed from life support, etc., but in fact 87 percent survived to discharge, whereas only 47 percent of the prenatally diagnosed infants survived to discharge.<sup>12</sup>

Clearly, lethal language and the acceptance of limited care at birth appear to affect survivability by withholding care, which may ultimately lead to an early death. Moreover, the research also supports the need to fully evaluate the living newborn before making any medical decisions, because testing conducted prenatally may be insufficient to guide complex medical decision making.<sup>13</sup>

Despite all of this evidence, why are babies with trisomy 13 and 18 so often characterized as incompatible with life? Medical researchers note that lethal language around diagnoses like trisomy 13 and 18 often reflects the judgment on the part of a medical provider that a life lived with a significant disability is not worth living.<sup>14</sup> In our work we find that the conversations medical providers have with the parents of infants with trisomy 13 and 18 (both prenatally and postnatally diagnosed) often focus on quality-of-life considerations, whether life-saving measures are appropriate, or even whether basic care such as feeding is warranted on the basis of the child’s significant intellectual disability. The Buffkins were told by their doctors that although some children with trisomy 18 do live, “they are vegetables with no real quality of life.”<sup>15</sup>

### Need for Complete and Accurate Information

Every day in our work we see how important it is for parents to have the best, most accurate medical information to make informed decisions for their baby with a prenatal diagnosis. When asked if she felt like her doctors gave her

sufficient information to make the best care judgments for Emmy, Kristen Buffkin observed, “My medical providers never pressured me into any decision. They presented me with all the options . . . and said they would support whichever choice I made, but they were very negative, offered no hope or support for my daughter, and quite frankly, they presented me with incorrect statistics. So, while they appeared to support me on the surface, the false information, and constant dismal outlooks were pushing me to make decisions I may not have made had I known all the facts.”<sup>16</sup> Often parents feel as if their decisions about the care of infants with a life-limiting prenatal diagnosis is being managed on the basis of both the negative expectations of medical providers and the presumption of lethality.

### Welcoming Our First Baby

The effect of “Ethical Care of Infants” on parental advocacy was immediately evident in August 2019. Gesine and Fernando Alvarez had been told that their baby Mila was “incompatible with life” when a twelve-week screening test indicated a risk of trisomy 13. Gesine remembers, “My [obstetrician] told me that I should start all over again . . . that my baby would most likely die in utero or at birth or shortly after, and if she didn’t die, she would need 24/7 care.”<sup>18</sup>

A transfer to a Catholic hospital offered a more supportive environment in which to carry to term. However, although Gesine was given information about the need for a birth plan, there was no process for supporting her in preparing one; she described sorting through the options on her own as “overwhelming.” She felt that the first real guidance for a birth plan came at thirty four-weeks’ gestation during the last week of July when she found *Be Not Afraid* online and learned that Catholic ethics addressed the issue of care for babies like Mila. The Alvarazes were completely committed to giving Mila every opportunity to live: “She deserved to get all the help we could give her because we love her and even with a diagnosis like Trisomy 13 she had the right to life.”

With her due date fast approaching, the plan for Mila’s birth had to be written quickly. Using “Ethical Care of Infants” and relevant medical research provided by *Be Not Afraid*, the Alvarazes asserted that they wanted Mila treated like any other baby during labor and at birth. Their first goal was a live birth, and their second goal was to have their newborn daughter stabilized and evaluated before making any decisions regarding her medical care. One of Gesine’s doctors had been encouraging regarding Mila’s prognosis. However, because of the use of lethal language, there was concern about the institutional perspective of babies with trisomy 13 at the hospital where Mila would be born. It was not clear, but it seemed likely that the usual protocol for babies like Mila was to in fact wait for death.

Nevertheless, during a neonatology consult the Alvarazes were assured that as a result of their request Mila

would be treated like any other baby until a full evaluation was completed and the findings discussed. It has been our experience that often hospitals with palliative care or comfort care protocols will respond with flexibility to parents who have clearly stated and well-researched care plans asking for more than what might usually be provided to babies with life-limiting prenatal diagnoses.

When Mila arrived early on August 2, 2019, at only thirty-five weeks and two days’ gestation and weighing 4 lbs., 7 oz., the agreed-on birth and newborn care plan was put into effect. Gesine was given an antenatal steroid injection to help with lung development when it became obvious that Mila’s birth was imminent. While standard procedure for babies born before thirty seven-weeks’ gestation, this essential treatment is rarely offered to parents delivering a preterm infant with a life-limiting condition.

Gesine’s description of that morning provides encouragement that when parents request that their baby be treated like any other baby, medical providers can accommodate their wishes: “Everyone was already informed that we were on our way and that we had a birth plan and that they would respect our wishes. Nurses came in my room and everyone was touched by our situation and our plan. They respected our wishes and were very lovely.” Newborn Mila was taken to the neonatal intensive care unit for the evaluation, and then several hours after that, the “neonatologist came back and told us that she was doing just fine and that he was surprised how well she was doing. She showed everyone that each baby with T13 is unique, and maybe you couldn’t just presume that all babies with T13 would die.” Mila’s survival did not touch just her parents; babies who exceed a fatal prognosis can also change the perspective of medical providers. Ideally, Mila’s life has informed the care of the next infant with trisomy 13 delivered at that institution.

The insistence that Mila be stabilized and evaluated at birth enabled the Alvarazes to learn essential information about their daughter’s health. Mila was diagnosed with full trisomy 13 after a prenatal screening test and a follow-up amniocentesis. However, additional testing after birth revealed that she had only a partial form of trisomy 13, called mosaicism, in which only some of the cells have an extra thirteenth chromosome. Like most preterm infants Mila had issues with low blood sugar, temperature regulation, and minor jaundice in the first few days following birth, but she responded appropriately to treatment. Gesine explained, “In general, we were told that she was a ‘normal’ premature baby, and that she had even less trouble than a few premies they had seen who did not have a life limiting diagnosis.”

While it is impossible to know what would have happened in the absence of a care plan asking that their daughter be stabilized and treated as any other baby, if left untreated the typical complications that affect many preterm babies can result in death if not monitored and addressed. On August 7, 2019, Mila was discharged, and she is alive today.



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### Prenatal Diagnosis and Inherent Dignity

Since Mila's case, "Ethical Care of Infants" has been used to inform the care of several more babies. Some are from Catholic families, some not. One is an infant with trisomy 13, a mild congenital diaphragmatic hernia, a heart defect, and abdominal hernias, who is now stable and at home following two surgeries. Another baby with trisomy 13 and a heart defect is now stable and recovering well following her heart surgery. Anecdotally, we see that these babies do better than expected when offered the same care as other children.

Regardless of prognosis or outcome, the challenge for Catholics "is to continue to bear witness, by our words and actions, to the fact that a prenatal diagnosis does not affect the inherent dignity, the unique and unrepeatable human reality, of a baby."<sup>18</sup> Emmy's and Mila's parents wanted only for their babies to be treated as individuals worthy of care and not to be dismissed or denied their very personhood because of a so-called lethal diagnosis and related disability.

#### Notes

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