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## PRENATAL TESTING AND THE DENIAL OF CARE

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**I** felt betrayed. I felt as though they lied to us to get the blood test done,” said Joy Keith, whose son Oliver “was no longer a candidate for heart surgery because of his trisomy diagnosis.”<sup>1</sup> When an ultrasound taken at eighteen weeks revealed brain cysts that could be signs of trisomy 13 or trisomy 18, doctors recommended a blood test to confirm the diagnosis.<sup>2</sup> Trisomy 13 and 18 are genetic disorders that are caused by chromosomal abnormalities.

The Keiths, who had refused an amniocentesis because of the risk of miscarriage, reluctantly agreed to the blood test only after their doctor said that a diagnosis would ensure that the proper medical team was assembled to administer emergency treatment at birth. Little did the Keiths know that this test, which was proposed to help Oliver, would ultimately be the reason that doctors refused to consider him as a candidate for heart surgery or even basic care like fetal monitoring during labor.<sup>3</sup>

### Why Undergo Prenatal Testing?

**D**octors and parents may have very different motivations when it comes to prenatal screening. Parents often agree to prenatal tests without enough knowledge about their purpose to give genuine informed consent. Parents may not understand the difference between screening and diagnostic tests<sup>4</sup> or be prepared for the consequences of a poor diagnosis or prognosis.

Very few genetic conditions can be treated prenatally, so if a disability is found, the “cure” proposed by the medical team is frequently abortion. In our utilitarian culture, prenatal screening has increasingly become a search-and-destroy mission to detect and eliminate babies with disabilities as early in pregnancy as possible.<sup>5</sup> Pressure to abort quickly,

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before they have had time to process a poor diagnosis and grieve the loss of the healthy child they expected, can throw parents off their usual moral compass.

In fact, a study funded by Natera, the manufacturer of the Panorama NIPT (noninvasive prenatal testing), found that despite its high cost, NIPT is cost-effective because it identifies children with expensive special needs, especially those who have a high-survival-rate condition like Down syndrome.<sup>6</sup> In other words, abortion following a poor prenatal diagnosis makes NIPT a “good investment” for insurance companies and providers.

Most parents are simply looking for reassurance that their baby is healthy.

Parents—and sometimes even health care professionals—are not always clear on the difference between prenatal screening tests and prenatal diagnostic tests. Screening can indicate only that a baby *may* have a particular condition, whereas a positive result on a diagnostic test confirms that the baby *does* have the condition.

Prenatal blood tests indicate probability only. Tests like amniocentesis and chorionic villus sampling, which carry a small risk of miscarriage, are needed to confirm a diagnosis. In other words, a positive result on a prenatal screening blood test does not definitively mean that the baby has a genetic anomaly.

### Newer Noninvasive Prenatal Testing

**O**ne screening test of particular concern is cell-free fetal DNA testing (also called NIPT), which is offered in the first trimester of pregnancy. These are expensive brand-name tests, with prices running into thousands of dollars. Insurance may not pay for the tests, which are aggressively marketed to expectant parents, including mothers who are considered at low risk of having a baby with a genetic condition. NIPT is typically used in place of the older triple and quad screen tests.

Promoted as being up to 99 percent accurate, independent laboratory studies have found that a positive result on NIPT can be incorrect 50 percent of the time or more.<sup>7</sup> The FDA does not regulate NIPT, and manufacturer claims have not been verified. The rarer the condition and the younger the mother, the less likely it is that a positive NIPT result will be accurate. For example, the American College of Obstetricians and Gynecologists estimates that a positive NIPT result for trisomy 13 in a twenty-five-year-old mother is correct only 9 percent of the time, meaning that 91 percent of positive results for that group could be false.<sup>8</sup>

Despite these serious limitations, adverse NIPT results all too frequently lead parents to have an abortion<sup>9</sup> or doctors to alter treatment.

If a disability or potential disability is detected, the pressure to abort quickly may become intense. Although most parents undergo prenatal screening or testing with no plan to abort on the basis of the results, 80 percent decide to abort after being told their unborn baby has a severe congenital anomaly.<sup>10</sup> Counseling from physicians is often directive, and parents may be encouraged to terminate on the basis of the doctor's personal biases. A survey conducted by the American College of Obstetricians and Gynecologists found that 90 percent of the doctors who responded considered abortion to be a justifiable response to uniformly fatal fetal anomalies. Sixty-three percent considered abortion to be a justifiable response to nonfatal anomalies.<sup>11</sup>

Parents, however, want a better option than abortion. When offered perinatal hospice support, about 80 percent of parents in the United States choose to carry their child to term.<sup>12</sup> In a survey conducted by Be Not Afraid, a nonprofit organization that provides comprehensive support to parents who are carrying their baby to term after an adverse prenatal diagnosis, 100 percent of respondents said they would encourage other parents in their situation to carry to term.<sup>13</sup> Carrying to term is physically safe for mothers, and studies have found that "there appears to be a psychological benefit to women to continue the pregnancy following a lethal fetal diagnosis."<sup>14</sup>

### Prenatal Diagnosis and Denial of Care

The Keiths "felt like Ollie was being discriminated against because he had trisomy 18."<sup>15</sup> This experience is not unique. On numerous occasions, parents who refused to abort a baby with a confirmed or suspected congenital anomaly found that their child was denied treatment that would be offered to other babies, including the most routine procedures, such as fetal monitoring during labor and an emergency cesarean section for fetal distress.<sup>16</sup> In the case of the Keiths, their son Oliver was denied routine care during labor as well as the heart surgery that the same doctors had said would be necessary before the trisomy 18 diagnosis.<sup>17</sup>

Babies with developmental disabilities are often denied surgery not because they are poor candidates for the procedure but because the medical community does not deem their lives worth saving: "All I wanted was for them to offer Ollie what they would offer any other baby. If surgery was necessary, then do it. I felt like Ollie was being discriminated against because he had trisomy 18. I felt like they didn't think he was worthy of being saved or able to be saved."<sup>18</sup> Looking back on her son's brief life, Joy has no regrets about her decision to give Oliver every chance at life she could: "He was beautiful and loved, and it was a privilege to fight for him to get the care he needed. I am so thankful we were chosen to be Ollie's parents."<sup>19</sup>

### "Incompatible with Life"

Other parents face a different type of obstacle. When a prenatal ultrasound revealed that Kayelee Childers

had an atrial septal defect (ASD) and a ventricular septal defect (VSD), her parents, Jesse and Natalie, prepared themselves for their baby girl to have heart surgery several months after birth. VSDs are the most common congenital heart defect in newborns, and according to the American Heart Association, the long-term prognosis following repair is excellent.<sup>20</sup>

Doctors at the regional children's hospital told the parents that additional scans after Kayelee's birth would clarify the severity of her heart defects, but surgery could probably wait until she was about four months old. Her parents were led to believe that she would automatically be a candidate for routine VSD and ASD repair. Everything changed after Kayelee's birth on January 12, 2017: "They told us they couldn't keep our daughter in the NICU anymore because they needed the room for another baby. That was a very hard thing to hear."<sup>21</sup>

The Childers declined prenatal genetic screening during Natalie's pregnancy, because they knew that the results would not change how they felt about their baby. However, genetic tests were ordered after doctors observed that baby Kayelee clenched her fists and displayed other traits of trisomy 18 after birth. The results that came in two days later changed the entire course of Kayelee's short life.

It never occurred to Kayelee's parents that the results of the genetic tests would prevent the treatment of Kayelee's heart condition. But following the trisomy 18 diagnosis, the hospital staff informed them that their baby was no longer a candidate for heart surgery, not because her heart condition had changed since the ultrasound but because she had trisomy 18. Baby Kayelee was not denied surgery because she was too small or unable to breathe independently or because of the complexity of her case. She was denied treatment because she had trisomy 18. The disability disqualified Kayelee from heart surgery because of a judgment about the value of her life, not because of any change in her medical condition.

Parents who receive a serious prenatal or neonatal diagnosis are often told that their baby's disabilities are "incompatible with life" or that the baby has a "fatal fetal anomaly." The label "incompatible with life" often reflects a physician's judgment of quality of life, not an actual medical diagnosis. Whatever the intention of the individual using it, the language dehumanizes the baby and may encourage abortion or the withdrawal of life-sustaining care. This is why a group of medical professionals launched the Geneva Declaration on Perinatal Care, a global statement calling for use of the term to end.<sup>22</sup> "Incompatible with life" becomes a self-fulfilling prophecy when parents carry their baby to term and treatments offered to other babies are withheld from theirs. It simply is not known at this point what the survival rate would be for babies with trisomy 13 and 18 if medically indicated treatments were fully considered in each case.

Natalie Childers said that from the moment of diagnosis, "everything was a downward spiral."<sup>23</sup> Although Kayelee had been a candidate for a routine heart repair, following the trisomy 18 diagnosis, her parents were told to stop

treatment and let her die. The medical team never asked Natalie and Jesse what their wishes were for Kayelee's care.

In the NICU, baby Kayelee was receiving prostaglandin to manage the aortic stenosis in her heart. Prostaglandin is commonly administered to keep blood vessels open in infants with congenital heart defects who are awaiting surgery or other repair. Physicians wanted to discontinue the prostaglandin that was helping Kayelee's heart to function, and they told her parents there was nothing more that could be done for her, because her diagnosis was incompatible with life.

Hospital staff then said that since they had decided there was nothing else they could do for Kayelee, they would no longer be able to keep her. The Childers said that one of the most frustrating aspects of their daughter's medical care was that physicians "gave up so easily. They just wanted to move [Kayelee] out."<sup>24</sup>

### A Search for Life-Saving Surgery

Kayelee's parents refused to discontinue the prostaglandin and, on the advice of a family member who was a NICU nurse, insisted that Kayelee be transferred to another hospital. Unlike the hospital where Charlie Gard was treated, Kayelee's hospital was willing to release her, although physicians were unwilling to refer her to another children's hospital. Babies with trisomy 13 or 18 are able to obtain heart surgeries in some states, so a referral might have offered Kayelee a chance at life.

Kayelee was transferred to a smaller community hospital near her family's home. However, this facility did not have the necessary pediatric cardiology services to repair Kayelee's heart and therefore was only a temporary solution while her parents desperately searched for a hospital willing to perform the surgery. Ultimately, the baby girl with "the biggest blue eyes and cute little nose" died in her mother's arms on February 2, 2017. No heart repair was ever performed.<sup>25</sup>

### Why Are These Babies Denied Care?

Lack of up-to-date information about a particular disability can affect the counseling physicians offer parents following a prenatal or neonatal diagnosis. Far too many parents have been told to take their baby home to die instead of being referred to a specialist to determine an appropriate course of care.

Speaking at the Perinatal Conference in Dublin in 2016, neonatologist Martin McCaffrey of the University of North Carolina discussed the inconsistencies between physician training and lived experiences with babies who have trisomy 13 and 18. He cited a 2016 study published in the *American Journal of Medical Genetics* that found that babies who survived the first year of life had more than an 80 percent chance of living until age five.<sup>26</sup> This finding was at odds with his medical school training, in which he was taught that babies with trisomy 13 or 18 always died. In fact, the five-year survival rate for babies with trisomy 18 (12.3 percent) is similar to the five-year survival rate for

patients with lung cancer (10–17.7 percent).<sup>27</sup> Yet patients with lung cancer are aggressively treated, while babies with chromosomal anomalies are routinely denied potentially life-saving or life-extending treatment.

Physicians' aversion to risk is another factor that contributes to their decision to deny surgical care to babies with disabilities. In April 2017, the *Journal of Thoracic and Cardiovascular Surgery* reported that "a recent poll of pediatric cardiac surgeons in the United Kingdom suggested that *public reporting also may be associated with risk aversion* in this population. Slightly less than one-third of surgeons in the anonymous poll reported recommending nonsurgical treatment because they feared the impact of mortality on their publicly reported outcomes."<sup>28</sup>

### Informed Consent Is Essential

Babies whose diagnoses are labeled "incompatible with life" are also at risk for being denied basic life-saving treatment under medical centers' futility policies. This was the case for Simon Crosier, a baby with trisomy 18 who died after being denied resuscitation. After his death, Simon's parents learned that a DNR (do-not-resuscitate) order had been placed in his chart without their consent or knowledge. The Crosiers were also deeply dismayed to discover that their baby had been provided only "comfort" feeding, an insufficient amount of food to sustain life. As Simon's mother, Sheryl Crosier, said, "If Simon hadn't stopped breathing, he would have been starved to death."<sup>29</sup>

The Crosiers' loss has turned into a legislative victory intended to prevent more lives from being lost because of secret DNR orders. Simon's Law requires that parents be informed verbally and in writing before a DNR is placed in their child's file and that they be given the opportunity to consent to or decline the DNR. Procedures are in place for court hearings to settle disputes between families and medical providers. Additionally, the law mandates that any patient may request and obtain a copy of a medical facility's futility policy.<sup>30</sup> Simon's Law was signed by Kansas governor Sam Brownback in April 2017.<sup>31</sup>

Parents deserve straightforward, accurate, and current medical information about their child's condition to empower them to be informed partners in their child's medical treatment. When Kayelee Childers was diagnosed with trisomy 18, the genetic counselor handed her family a brochure about her condition, informed them that Kayelee had only a slim chance of living to one year, and left the room. Natalie Childers said they were "shocked that they didn't get more detail from the geneticist" or have a chance to ask questions. There was "no counseling, no compassion, and we were never asked for our input."<sup>32</sup>

In the wake of Kayelee's death, her parents remain frustrated at how quickly doctors gave up on her after her genetic diagnosis. As Kayelee's mother said, "Hospitals should be doing anything they can to save a life, to promote life."<sup>33</sup> Yet all too often, the label "incompatible with life" becomes a justification to abandon attempts to preserve or prolong life, making it a self-fulfilling prophecy.

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The views expressed here are those of the individual authors and may advance positions that have not yet been doctrinally settled. *Ethics & Medics* makes every effort to publish articles that are consonant with the magisterial teachings of the Catholic Church.

### Notes

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