

## **Stories of Premature Birth and Lethal and Non-Lethal Fetal Anomalies Involving Fetal Surgery, Perinatal Hospice**

### **Fetal Surgery:**

- Wisconsin, 2012: April Leffingwell received the prenatal diagnosis at 20 weeks that her son had a rare and possibly life-threatening condition called CCAM, and that he had a large tumor in his lung. At 25 weeks in utero, doctors removed the tumor during fetal surgery. Eight weeks later, Elijah was born, and in 2014 he turned two years old.<sup>1</sup>
- Kentucky, 2006: Colleen and Blake received a prenatal diagnosis at 20 weeks that their son had a life-threatening case of hydrocephalus and spina bifida. Skilled surgeons performed fetal surgery on baby Nate at 23 weeks in utero and then he received intensive care upon birth. In 2015 Nate finished 3rd grade and was on to 4th.<sup>2</sup>
- Georgia, 1999: Julie and Alex Armas were given the prenatal diagnosis at 15 weeks that their son had permanent nerve damage from an opening in his spine due to spina bifida. Doctors said half of babies with spina bifida are aborted, but they refused. At 19 weeks post-fertilization, Samuel was operated on in utero, and in 2016 he was a healthy 16-year-old high school student and basketball player.<sup>3</sup>
- Texas, 2016: Margret Boemer received the prenatal diagnosis of sacrococcygeal teratoma at her 16-week ultrasound. While some doctors advised abortion, she chose fetal surgery at 21 weeks post-fertilization in which Baby LynLee Hope was taken out of the uterus to remove the tumor nearly her size. After the surgery, LynLee spent 12 more weeks in utero to be “born again” full term and fourth months later was successfully meeting her health milestones.<sup>4</sup>
- Vermont, 2013: Katie Rice was given the prenatal diagnosis at her 20-week ultrasound of a rare tumor on her baby’s heart called intrapericardial teratoma. Doctors told Katie that her health was at risk, and she may need to terminate her pregnancy. Instead Katie chose fetal surgery and baby Tucker was operated on at 22 weeks post-fertilization. This was to be the first prenatal heart surgery which removed a life-threatening tumor. Tucker is now three years old and likes sandboxes, monster trucks, water parks, and riding his bike.<sup>5</sup>
- Maryland, 2013: At their 19-week ultrasound, Jackie and Gideon Oberio received the prenatal diagnosis of the most severe form of spina bifida, myelomeningocele. Jackie and baby Audrey underwent fetal surgery, and 12 weeks later Audrey was born. As of 2016, Audrey was a happy three-year-old who attends preschool, walks independently, and loves life.<sup>6</sup>
- Pennsylvania, 2012: Rachel and Govind Vinjamuri were given the life-threatening prenatal diagnosis of twin-twin transfusion at their 17-week ultrasound. Rachel chose fetal surgery and days later underwent fetoscopic selective laser ablation. At 37 weeks, she gave birth to two healthy baby boys. In 2016 Aiden and Dillon turned 4 years old.<sup>7</sup>
- Florida, 1995. Felicia and Roberto Rodriguez were given the prenatal diagnosis congenital cystic adenomatoid malformation, a large mass growing in their baby’s left lung. The Rodriguez family choose to undergo an operation to remove the lesion at 20 weeks post-fertilization and were the

first to undergo fetal surgery at CHOP. Roberto Jr. was born 13 weeks later with a healthy set of lungs. This year he celebrated his 21<sup>st</sup> birthday.<sup>8</sup>

- Canada, 2017: Kristine Barry and husband Christopher Havill received the prenatal diagnosis of a severe complete transposition of the great arteries at their 20-week ultrasound. Kristine chose fetal surgery and a balloon atrial septoplasty was performed, the first time this kind of surgery was performed on an unborn baby with a congenital heart defect where the two main arteries are reversed. Five days later baby Sebastian was delivered naturally and one week after birth had open-heart surgery. Today he is a healthy baby at home in Ontario.<sup>9</sup>

### **Lethal/Life-Threatening Anomalies with Survival or Perinatal Hospice<sup>10</sup>:**

- New Jersey, 1998<sup>11</sup>: Wanda and Michael Fisher received the prenatal diagnosis of a congenital diaphragmatic hernia at their 17-week ultrasound. With less than 1% chance of survival, the physician recommended abortion. The Fishers chose to continue the pregnancy, and Michael Jr. was born at 36 weeks. After 2 surgeries and 40 days in N/IICU, he was able to move home. In 2015, Michael Jr. was in his high school's marching band and planned on becoming an electrical engineer.<sup>12</sup>
- 2016: Lyndsay and Matthew Brentlinger received the prenatal diagnosis of a severe congenital heart defect in one of their unborn twins. Their doctor predicted he would likely be stillborn, but Baby William beat the odds and was born with his sister Reagan. The family moved home with hospice care for William, and 11 days after birth, William passed away. Lyndsay said that her family felt blessed to be able to have the time they did to get to know their son.<sup>13</sup>
- Alabama, 2015: Talia Gates, an OB-GYN, and her husband, Josh, received the prenatal diagnosis of Thanatophoric Dysplasia, a rare skeletal disorder, at the 20-week ultrasound of their daughter. Their doctor advised them to carry her to term, as she was "happy as a lark in there." They did, and Talia gave birth to baby Aubrey at 36 weeks. As Aubrey would not survive long outside of the womb, the family chose "comfort care" and were able to hold their baby for nearly an hour. They heard her voice and gazed back into her eyes as she looked at her parents and big brother. Talia remembered, "at that moment, all I felt was peace... It was the most beautiful 49 minutes of my life."<sup>14</sup>
- Rhode Island, 2014: Sonia and Rony Morales were given a prenatal diagnosis that their daughter had anencephaly and was missing parts of her brain and skull. Doctors said baby Angela was "incompatible with life" and suggested abortion. The Morales' refused, and Angela underwent a successful brain surgery in May of 2014. In 2016 she turned two years old.<sup>15</sup>
- Pennsylvania, 2000: Retired Philadelphia Eagles player Vaughn Hebron and wife Kim were given a prenatal diagnosis at five months of twin-twin transfusion, a life-threatening condition. They decided to continue with the pregnancy, though doctors said there was a 70% chance one or both twins would die. Son Savaughn received intensive care, and now he and his brother are healthy teenagers.<sup>16</sup>
- Florida, 2013: Lindsey and Kevin Dennis were given a prenatal diagnosis at 20 weeks that their daughter had a fatal type of anencephaly. Doctors offered abortion, but instead they welcomed Sophie who lived for 10 hours surrounded by the love of family and friends.<sup>17</sup>
- Washington, 2005: Jeanne and Steve Deibert received a prenatal diagnosis that their son had Trisomy 18, a chromosomal anomaly that causes heart and kidney problems so severe that less than 10% of babies survive the first year. Deciding against abortion, Jeanne gave birth to baby Robbie who lived for 29 days during which time the hospital provided perinatal hospice care for him. Family, friends, and their priest visited them, and because of the support Jeanne described the experience as serene.<sup>18</sup>

- Pennsylvania, 2008: Senator Rick Santorum and wife Karen were given a prenatal diagnosis that their daughter had life-threatening Trisomy 18. Bella survived with medical care, and turned nine years old this May.<sup>19</sup>
- Puerto Rico, 2016: Grammy winner Wisin and his wife Yomaira Ortiz were given the prenatal diagnosis at 20 weeks that their daughter had Trisomy 13. Being advised to terminate the pregnancy, the couple instead welcomed their daughter's birth and were grateful to spend one month with baby Victoria before she died. Mrs. Ortiz has since spoken out against choosing abortion even if advised by one's physician.<sup>20</sup>

### **Very Premature Birth:**

- Ohio, 2017: Dakota Harris was born on January 22, 2017 at **19 weeks post-fertilization**. Weighing 1 lb, little Dakota beat all odds and left the hospital this May at a healthy 7 lbs. 5 oz. Her parents, Cleveland Cavaliers guard J.R. Harris and his wife, Jewel, have been public about their family's journey hoping to show others they are not alone.<sup>21</sup>
- Iowa, 2012: Micah Pickering was born at **20 weeks post-fertilization** on July 25, 2012. He underwent heart surgery and spent four months in the neonatal intensive care unit before his parents, Danielle and Clayton, were finally able to bring him home. Micah is now a healthy five-year-old and is off to Kindergarten this fall.<sup>22</sup>
- Israel, 2016: Baby Aharon was born at **20 weeks post-fertilization**. After spending almost five months in the hospital, he was able to leave in good health.<sup>23</sup>
- Germany, 2010: Freida Mangold was born at **19 weeks and five days** post-fertilization into the pregnancy after her mother suffered complications. After receiving intensive care, she was able to go home with "no indication that she will not be healthy" according to her doctor. She is Europe's youngest premature baby known to survive.<sup>24</sup>
- Florida, 2006: Amillia Taylor was delivered by emergency C-section when she **was 21 weeks and six days post-fertilization**. She received medical care and survived. As of 2007, she showed no signs of long-term effects of prematurity.<sup>25</sup>
- Canada, 1987: James Gill was born at **19 weeks and five days post-fertilization** and weighed just over one pound. His mother suffered complications, so before his birth, doctors prepared for a stillborn. He is known as the most premature baby to survive and is now 30 with no seeming severe health condition.<sup>26</sup>
- England, 2014: Bella Davison was born at **21 weeks post-fertilization**, weighing one pound. Doctors said she wouldn't live through the night, but she did and after six months of medical care, she was healthy enough to go home. Bella turned three this past July.<sup>27</sup>
- New Jersey, 2013: Faith Massey was born prematurely at **21 weeks post-fertilization** due to a placenta infection. Weighing only 15 ounces, she received months of intensive care and was finally able to go home healthy.<sup>28</sup>
- Virginia, 2008: Charlotte Ryun was born at **22 weeks post-fertilization** due to a placenta complication and major bleeding in her mother. Charlotte underwent intensive care, and in 2015 she turned seven years old and was in good health.<sup>29</sup>

<sup>1</sup><http://dailysignal.com/2014/12/09/elijahs-story-life-saved-birth/>

<sup>2</sup> <http://www.benotafraid.net/Articles/Detail/ArticleId/32/Let-Me-Decide>; <http://whatnatesaidtoday.blogspot.com/>

<sup>3</sup> <http://illinoisreview.typepad.com/illinoisreview/2012/01/samuel.html>;

<http://www.foxnews.com/story/2009/05/06/ten-years-later-boy-hand-hope-continues-to-spark-debate/>;

<http://www.nationalrighttolifenews.org/news/2013/04/an-update-on-samuel-arnas-a-flash-of-life/#.VUzi3 IVikp>;

<http://specials.myajc.com/hope-faith/>

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- <sup>4</sup> <http://www.cnn.com/2016/10/20/health/baby-born-twice-fetal-surgery/index.html?sr=fbCNN102116baby-born-twice-fetal-surgery1143AMStoryLink&linkId=30195463>; [https://www.washingtonpost.com/news/speaking-of-science/wp/2016/10/26/the-baby-who-was-born-twice/?utm\\_term=.44ac2e62116c](https://www.washingtonpost.com/news/speaking-of-science/wp/2016/10/26/the-baby-who-was-born-twice/?utm_term=.44ac2e62116c);  
<http://www.foxnews.com/health/2016/10/26/texas-baby-born-twice-meeting-growth-milestones-4-months-later.html>
- <sup>5</sup> [http://www.philly.com/philly/health/20161127\\_In\\_world\\_first\\_Philly\\_surgeons\\_remove\\_fetal\\_heart\\_tumor\\_during\\_pregnancy.html](http://www.philly.com/philly/health/20161127_In_world_first_Philly_surgeons_remove_fetal_heart_tumor_during_pregnancy.html); [https://www.eurekalert.org/pub\\_releases/2016-10/chop-fss102416.php](https://www.eurekalert.org/pub_releases/2016-10/chop-fss102416.php)
- <sup>6</sup> Audrey's parents documented their experience in home videos as a love letter to their unborn baby:  
<http://www.chop.edu/video/fetal-surgery-milestone-oberio-family-story>; <http://www.chop.edu/stories/spina-bifida-and-fetal-surgery-audreys-story>
- <sup>7</sup> <http://www.chop.edu/stories/twin-twin-transfusion-syndrome-ttts-aiden-and-dillon>;  
<https://www.youtube.com/watch?v=YqJO5FXJdF0>
- <sup>8</sup> [http://www.chop.edu/stories/congenital-cystic-adenomatoid-malformation-ccam-roberto-story?utm\\_source=Social&utm\\_campaign=Roberto%27s%20story&utm\\_medium=Facebook&utm\\_content=Roberto%27s%20Story](http://www.chop.edu/stories/congenital-cystic-adenomatoid-malformation-ccam-roberto-story?utm_source=Social&utm_campaign=Roberto%27s%20story&utm_medium=Facebook&utm_content=Roberto%27s%20Story)
- <sup>9</sup> <http://www.cbc.ca/news/health/baby-sebastian-in-utero-heart-surgery-1.4221750>; <http://barrie.ctvnews.ca/in-utero-surgery-gives-a-barrie-baby-good-heart-start-in-life-1.3519652>;  
<https://www.thestar.com/news/gta/2017/07/26/ground-breaking-surgery-saves-babys-life-at-sickkids-hospital.html>
- <sup>10</sup> [Perinatalhospice.org](http://www.perinatalhospice.org) is an extensive privately-run online resource listing perinatal hospice programs and groups per U.S. state and internationally. For testimonies: <http://www.perinatalhospice.org/parent-voices.html>
- <sup>11</sup> <https://www.camdendiocese.org/encountering-mercy-feed-the-hungry/>
- <sup>12</sup> <http://www.chop.edu/stories/congenital-diaphragmatic-hernia-cdh-michael-jr-s-story>;  
<http://www.chop.edu/fetal20/video/michaels-story-congenital-diaphragmatic-hernia>;  
<https://www.youtube.com/watch?v=LwAHeoS5uNo>
- <sup>13</sup> <https://www.today.com/parents/twin-photo-shoot-helps-family-remember-baby-who-died-t106976>
- <sup>14</sup> <https://www.today.com/parents/most-beautiful-49-minutes-my-life-mom-shares-story-infant-t80221>;  
<http://storyofaubreylea.blogspot.com/>
- <sup>15</sup> <http://www.people.com/article/miracle-baby-angela-morales-anencephaly-celebrates-first-birthday>;  
<http://www.nationalrighttolifenews.org/news/2014/12/baby-angela-continues-to-defy-odds-turns-eight-months/#.VUzXHvIVikq>; <https://www.facebook.com/ourbabyANGELA/>
- <sup>16</sup> <http://www.chop.edu/stories/twin-twin-transfusion-syndrome-savaughn-and-savions-story#.VLBPsvF8T->
- <sup>17</sup> <http://vaporandmist.com/why-we-chose-to-carry-sophie/>
- <sup>18</sup> [http://www.trisomy18.org/site/PageServer?pagename=whatisT18\\_whatis](http://www.trisomy18.org/site/PageServer?pagename=whatisT18_whatis);  
<http://www.nbcnews.com/id/23682263/#.VK6WUCvF8T8>; <http://www.newsweek.com/hospice-care-babies-84583>
- <sup>19</sup> <http://townhall.com/columnists/ricksantorium/2013/03/19/celebrating-bella-our-gift-from-god-n1537653/page/full>
- <sup>20</sup> <http://www.foxnews.com/entertainment/2016/09/30/puerto-rican-rapper-wisin-reveals-one-month-old-daughter-has-died.html>; <http://www.ibtimes.com/rapper-wisin-mourns-death-daughter-victoria-trisomy-13-genetic-disorder-touching-post-2424612>
- <sup>21</sup> <http://www.espn.com/video/clip?id=19570142>; <https://www.mykotabear.com/>;  
<http://www.eonline.com/news/856799/j-r-smith-brings-prematurely-born-baby-girl-dakota-home-from-hospital-nicu>; <http://www.cnn.com/2017/01/09/health/jr-smith-daughter-premature/index.html>
- <sup>22</sup> <https://www.nytimes.com/2015/05/07/health/premature-babies-22-weeks-viability-study.html?mcubz=3>  
<https://www.catholicnewsagency.com/news/us-house-to-vote-on-banning-abortion-after-20-weeks-94031>
- <sup>23</sup> <http://www.timesofisrael.com/22-week-preemie-is-youngest-ever-to-survive-in-israel/>
- <sup>24</sup> <http://healthland.time.com/2011/05/27/baby-born-at-21-weeks-survives-how-young-is-too-young-to-save/>
- <sup>25</sup> <http://www.dailymail.co.uk/femail/article-1021034/The-tiniest-survivor-How-miracle-baby-born-weeks-legal-abortion-limit-clung-life-odds.html>
- <sup>26</sup> <http://www.canada.com/topics/bodyandhealth/story.html?id=db8f33ab-33e9-429f-bedc-b6ca80f61bd>;  
<http://www.guinnessworldrecords.com/world-records/67461-most-premature-baby>
- <sup>27</sup> <http://www.dailymail.co.uk/health/article-2901720/Baby-born-just-ONE-week-legal-abortion-limit-weighing-just-1lb-finally-goes-home-six-months-hospital.html>;  
[https://www.facebook.com/permalink.php?story\\_fbid=1426457600773027&id=690845721000889](https://www.facebook.com/permalink.php?story_fbid=1426457600773027&id=690845721000889)
- <sup>28</sup> <http://abcnews.go.com/Health/mom-faith-survival-hospitals-tiniest-baby/story?id=20100148&page=2>
- <sup>29</sup> <http://www.cbn.com/tv/1580098951001>