



Stories of Premature Birth and Fetal Anomalies Involving Fetal Surgery, Perinatal Hospice

The following is a compilation of public stories shared by families who have been affected by a prenatal diagnosis of fetal anomaly or very premature birth. [View sorted by diagnosis.](#)

Fetal Surgery

- Wisconsin, 2021: At her 20-week ultrasound, Mallorie DeRuyter and her husband Chris found out that their son, Max, had *spina bifida*. After meeting with specialists at the Fetal Health Institute at Lurie Children's Hospital in Chicago, Mallorie and Chris agreed to the fetoscopic option for the surgery, becoming the first to undergo fetoscopic spina bifida repair at Lurie Children's Hospital. After a delicate six-hour surgery, the ultrasound revealed that it went smoothly. Max was delivered in February and loves to kick and move his toes.¹
- Dubai, 2019: Doaa and Ali Ghaib learned their daughter had a *heart defect* at their 20-week ultrasound. They traveled more than 22 hours to Cleveland's Rainbow Babies and Children's Hospital, where doctors inserted a needle through Doaa's abdomen and into baby Nadine's heart, by which they were able to inflate a small balloon to open a closed heart valve. In March 2021, Nadine turned two years old. She is now a happy toddler at the family home in Montreal, Quebec.²
- Ohio, 2018: Heather Catanese learned at her 22-week ultrasound that the blood in her son's heart was flowing in the wrong direction and doctors confirmed a diagnosis of *hypoplastic left heart syndrome (HLHS)*. Left untreated, children born with this condition have about a 10 percent chance of surviving six months after birth. The Catanese family decided to try fetal surgery. At 24 weeks gestational age, doctors inserted a needle through Heather's abdomen and into baby Lorenzo's heart. A small balloon was inflated to expand the aortic valve, to aid development of the left side of his heart. Heather gave birth to Lorenzo just shy of 39 weeks, and he went home with the family four days after birth. He is now a thriving two-year-old.³
- 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. This was 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. He went home a healthy baby with mom and dad.⁴

- Texas, 2016: Margaret Boemer received the prenatal diagnosis of *sacroccygeal teratoma* at her 16-week ultrasound. While some doctors advised abortion, she chose fetal surgery at 23 weeks 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 in 2017 she turned one year old.⁵
- 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 2018, Audrey is a happy five-year-old who attends school, enjoys dancing, and loves life.⁶
- 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 24 weeks gestational age. This was to be the first prenatal heart surgery which removed a life-threatening tumor. Tucker, healthy at three years old in 2016, likes sandboxes, monster trucks, water parks, and riding his bike.⁷
- Pennsylvania, 2012: Rachael and Govind Vinjamuri were given the life-threatening prenatal diagnosis of *twin-twin transfusion syndrome* at their 17-week ultrasound. Rachael 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 four years old.⁸
- Wisconsin, 2012: April Leffingwell received the prenatal diagnosis at 20 weeks that her son had a rare and possibly life-threatening condition called *congenital cystic adenomatoid malformation (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. In 2014, he turned two years old.⁹
- 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.¹⁰

- 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 21 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.¹¹
- Florida, 1995: Felicia and Roberto Rodriguez were given the prenatal diagnosis *congenital cystic adenomatoid malformation (CCAM)*, a large mass growing in their baby's left lung. The Rodriguez family choose to undergo an operation to remove the lesion at 22 weeks gestational age and were the first to undergo fetal surgery at Children's Hospital of Philadelphia. Roberto Jr. was born 13 weeks later with a healthy set of lungs. In 2017, he celebrated his 22nd birthday.¹²

Life-threatening Fetal Anomalies with Survival or Perinatal Hospice¹³

- Ohio, 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 William.¹⁴
- Virginia, 2016: A few weeks after Allison Seabolt's 20-week ultrasound for her daughter Penelope, she received a prenatal diagnosis of Down syndrome and *complete atrioventricular canal defect*. Because of this rare heart condition, Penelope would need open heart surgery shortly after birth. When she was two months old, Penelope underwent surgery at Children's National Hospital, after experiencing symptoms that warned the heart condition was affecting her growth and ability to eat. The surgery and recovery went smoothly. Today, Penelope loves to spend time with her older sisters.¹⁵
- 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.¹⁶
- 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.”¹⁷

- 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. Sonia and Rony refused, and Angela underwent a successful brain surgery in May of 2014. She defied expectations, bringing joy to her family for more than two-and-a-half years.¹⁸
- Virginia, 2013: At a 19-week scan, baby Isaac’s parents learned his brain was not developing normally. They were told they “had five weeks to decide.” With the assistance of perinatal hospice, Isaac was born on August 14, 2013 with no complications except an apricot-sized *encephalocele*, which was removed the following day. In 2018, Isaac completed two years of special education preschool. He loves to play outside.¹⁹
- Florida, 2013: Lindsey and Kevin Dennis were given a prenatal diagnosis at 20 weeks that their daughter had *anencephaly*. Doctors offered abortion, but instead Lindsey and Kevin welcomed Sophie, who lived for 10 hours surrounded by the love of family and friends.²⁰
- 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 in 2020 she turned 12 years old.²¹
- 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 percent of babies survive the first year. Deciding against abortion, Jeanne gave birth to baby Robbie who lived for 29 days, during which time perinatal hospice care was provided. Family, friends, and their priest visited them, and because of the support Jeanne described the experience as serene.²²
- Kentucky, 2002: Before his birth, the West family knew their son Braden’s brain was not developing normally. They chose life and Cheri West gave birth to Braden, who was diagnosed with *Pfeiffer syndrome*. Doctors predicted he would live no more than 18 months; but in 2020, he graduated from high school and volunteers as an airman with the Civil Air Patrol.²³
- Pennsylvania, 2000: Retired Philadelphia Eagles player Vaughn Hebron and wife Kim were given a prenatal diagnosis at five months of *twin-twin transfusion syndrome*, a life-threatening condition. They decided to continue with the pregnancy, though doctors said there was a 70 percent chance one or both twins

would die. Son Savaughn received intensive care, and now he and his brother are healthy teenagers.²⁴

- New Jersey, 1998: Wanda and Michael Fisher received the prenatal diagnosis of a *congenital diaphragmatic hernia* at their 17-week ultrasound. With less than one percent chance of survival, the physician recommended abortion. The Fishers chose to continue the pregnancy, and Michael Jr. was born at 36 weeks. After two 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.²⁵

Very Premature Birth

- Florida, 2020: Jomary and Federico were expecting their first child when Jomary was placed on bed rest so their baby could remain in utero until at least **22 weeks gestational age**. Mom gave birth in May 2020 to Diana, who weighed only 12 ounces. Doctors believe initial estimates may have been incorrect, and that Diana may have been younger than 22 weeks gestational age at birth. After spending time in NICU, baby Diana is now at home with mom and dad.²⁶
- Minnesota, 2019: Yanling Chan was diagnosed with *gestational diabetes* and began bleeding soon after her 20-week ultrasound. She was put on bed rest and delivered baby Yishan by emergency C-section at **23 weeks gestational age**. The baby weighed only 520 grams at birth. In September 2020, he turned one year old and is meeting all the usual milestones.²⁷
- England, 2018: Twin brothers Jenson and Ruben Powell were born on August 17, 2018 at just **22 weeks and six days gestational age**, after their mother, Jennie, went to the hospital due to pain. Jenson, weighing 18.8 ounces was given a zero percent chance of survival in the first 48 hours, while Ruben, weighing 20.8 ounces, was given a 20-30 percent of survival. After receiving blood transfusions and eye surgery, among other operations, the twins beat the odds and celebrated their first birthday in August 2019.²⁸
- California, 2018: Baby Saybie was born prematurely at **23 weeks gestational age** due to mom's *pre-eclampsia*. She weighed only 8.6 ounces. She went home with her family after six months in NICU, without any need for oxygen or a feeding tube, weighing five pounds, six ounces.²⁹
- England, 2018: Kym Brown was diagnosed with *pre-eclampsia* and gave birth to baby Isabella at **24 weeks gestational age**. Weighing only about 12 ounces and having been given only a five percent chance of survival, Isabella was a fighter. After several surgeries, Britain's smallest baby is doing well at home with mom and dad, Ryan Evans.³⁰

- Ohio, 2017: Dakota Harris was born on January 22, 2017 at **21 weeks gestational age**. Weighing one pound, little Dakota beat all odds and left the hospital that May at a healthy seven pounds, five ounces. Her parents, former Cleveland Cavaliers guard J.R. Smith and his wife, Jewel, have been public about their family's journey, hoping to show others they are not alone.³¹
- Israel, 2016: Baby Aharon was born at **22 weeks gestational age**. After spending almost five months in the hospital, he was able to leave in good health.³²
- England, 2014: Bella Davison was born at **23 weeks gestational age**, weighing one pound. Doctors said she would not live through the night, but she did, and after six months of medical care, she was healthy enough to go home, where she continues to thrive.³³
- Texas, 2014: Lyla Stensrud was born at **21 weeks gestational age**. In 2018, she was a healthy four-year-old and was attending preschool.³⁴
- New Jersey, 2013: Faith Massey was born prematurely at **23 weeks gestational age** due to a *placenta infection*. Weighing only 15 ounces, she received months of intensive care and was finally able to go home healthy.³⁵
- Iowa, 2012: Micah Pickering was born at **22 weeks gestational age** 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 elementary school student.³⁶
- Germany, 2010: Frieda Mangold was born at **21 weeks and five days gestational age** 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.³⁷
- Virginia, 2008: Charlotte Ryun was born at **23 weeks gestational age** 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.³⁸
- Florida, 2006: Amillia Taylor was delivered by emergency C-section when she **was 21 weeks and six days gestational age**. She received medical care and survived. As of 2007, she showed no signs of long-term effects of prematurity.³⁹
- Canada, 1987: James Gill was born at **21 weeks and five days gestational age** and weighed just over one pound. His mother suffered complications, so before his birth, doctors prepared for a stillborn. Guinness World Records identifies James as the most premature baby to survive; he is now in his 30s with no seeming severe health condition.⁴⁰

- ¹ <https://www.wbay.com/2021/05/06/maxs-journey-from-spina-bifida-to-healthy-baby-boy/>.
- ² <https://www.news5cleveland.com/news/local-news/cleveland-metro/how-greys-anatomy-led-a-mother-from-dubai-to-cleveland-so-her-baby-could-receive-life-saving-surgery-in-utero>.
- ³ <https://www.liveaction.org/news/thriving-hypoplastic-left-heart-syndrome/>.
- ⁴ <http://www.cbc.ca/news/heart-surgery-performed-inside-the-womb-1.4224165>; <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>.
- ⁵ <http://www.cnn.com/2016/10/20/health/baby-born-twice-fetal-surgery/index.html>; <https://www.washingtonpost.com/news/speaking-of-science/wp/2016/10/26/the-baby-who-was-born-twice/>; <http://www.foxnews.com/health/2016/10/26/texas-baby-born-twice-meeting-growth-milestones-4-months-later.html>; <https://people.com/human-interest/miracle-baby-born-twice-celebrates-first-birthday/>.
- ⁶ Audrey's parents documented their experience in home videos as a love letter to their unborn baby: <http://www.chop.edu/stories/spina-bifida-and-fetal-surgery-audreys-story>.
- ⁷ 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.
- ⁸ <http://www.chop.edu/stories/twin-twin-transfusion-syndrome-ttts-aiden-and-dillon>; <https://www.youtube.com/watch?v=YqJO5FXJdF0>.
- ⁹ <http://dailysignal.com/2014/12/09/elijahs-story-life-saved-birth>.
- ¹⁰ <http://whatnatesaidtoday.blogspot.com>.
- ¹¹ <http://illinoisreview.typepad.com/illinoisreview/2012/01/samuel.html>; <http://specials.myajc.com/hope-faith/>.
- ¹² <https://www.chop.edu/stories/congenital-cystic-adenomatoid-malformation-ccam-roberto-s-story>; <http://www.facebook.com/ChildrensHospitalofPhiladelphia/photos/22-years-ago-today-roberto-rodriguez-jr-became-the-first-ever-fetal-surgery-pati/10157271303279498>.
- ¹³ Perinatalhospice.org is an extensive, privately run online resource listing perinatal hospice programs and groups by U.S. state, and internationally. For testimonies, see <https://www.perinatalhospice.org/parent-voices>.
- ¹⁴ <http://www.today.com/parents/twin-photo-shoot-helps-family-remember-baby-who-died-t106976>.
- ¹⁵ <https://childrensnational.org/visit/childrens-difference/our-stories/penelopes-story>; https://fredericksburg.com/news/local/superstar-patient-recovering-after-open-heart-surgery/article_237e4f06-4526-58ab-89ca-4104ca22da96.html.
- ¹⁶ <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>.
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- ¹⁸ <http://www.people.com/article/miracle-baby-angela-morales-anencephaly-celebrates-first-birthday>; <https://www.facebook.com/ourbabyANGELA/>; <http://www.providencejournal.com/news/20171217/providence-child-known-as-baby-angela-dies>.
- ¹⁹ https://edmarc.org/our_stories/isaac/.
- ²⁰ <https://www.abeautifulremembrance.com/blogs/news/10-precious-hours-written-by-lindsey-dennis>.
- ²¹ <http://townhall.com/columnists/ricksantorium/2013/03/19/celebrating-bella-our-gift-from-God-n1537653/page/full>; <https://www.liveaction.org/news/incompatible-with-life-bella-santorium/>; <https://www.liveaction.org/news/bella-santorium-doctors-incompatible-life-12/>.
- ²² <http://www.nbcnews.com/id/23682263/>; <http://www.newsweek.com/hospice-care-babies-84583>.
- ²³ <https://www.wfaa.com/article/syndication/heartthreads/braden-west-michele-linn-pfeiffer-syndrome-hospice-nurse/507-2f87509e-4689-4dbe-859b-11f64f11fa88>.
- ²⁴ <http://www.chop.edu/stories/twin-twin-transfusion-syndrome-savaughn-and-savions-story>.
- ²⁵ <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>.
- ²⁶ https://www.instagram.com/tv/CHQ_5YohQ1h/?igshid=1fehsqi8xx0cx.
- ²⁷ <https://www.childrensmn.org/2020/11/12/extremely-premature-infant-miracle-baby/>.

²⁸<https://www.bbc.com/news/health-50144741>;<https://www.bbc.com/news/uk-england-cornwall-49336192>;
<https://www.liveaction.org/news/britains-youngest-surviving-twin-boys-first-birthday/>

²⁹<https://www.sandiegouniontribune.com/news/health/story/2019-05-29/meet-saybie-the-worlds-smallest-baby>;
<https://www.facebook.com/sharpmariabirch/posts/baby-saybie-update-we-are-happy-to-share-this-sweet-photo-of-saybie-enjoying-lif/2768040479903942/>

³⁰<https://www.youtube.com/watch?v=8dUn0Tc9OhQ>;<https://www.dailymail.co.uk/news/article-6938689/Britains-tiniest-baby-born-weighing-0-76lbs-24-weeks-finally-goes-home.html>;
<https://www.thesun.co.uk/news/8894965/uk-tiniest-miracle-baby-home-born/>;
<https://www.mirror.co.uk/news/uk-news/britains-tiniest-baby-16-years-14435999>

³¹ <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>.

³² <http://www.timesofisrael.com/22-week-preemie-is-youngest-ever-to-survive-in-israel/>.

³³<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>.

³⁴<https://hcatodayblog.com/2018/12/06/will-you-try-mom-recalls-journey-of-most-premature-baby-at-methodist-childrens-hospital>.

³⁵ <http://abcnews.go.com/Health/mom-faith-survival-hospitals-tiniest-baby/story?id=20100148&page=2>.

³⁶<https://www.nytimes.com/2015/05/07/health/premature-babies-22-weeks-viability-study.html>;
<https://www.catholicnewsagency.com/news/us-house-to-vote-on-banning-abortion-after-20-weeks-94031>;
<https://pregnancyhelpnews.com/pain-capable-unborn-child-protection-act-sponsored-by-a-third-of-u-s-house>.

³⁷ <http://healthland.time.com/2011/05/27/baby-born-at-21-weeks-survives-how-young-is-too-young-to-save>.

³⁸ <http://www.cbn.com/tv/1580098951001>

³⁹<http://www.dailymail.co.uk/femail/article-1021034/The-tiniest-survivor-How-miracle-baby-born-weeks-legal-abortion-limit-clung-life-odds.html>.

⁴⁰<http://www.guinnessworldrecords.com/world-records/67461-most-premature-baby>;
<http://www.verywellfamily.com/worlds-smallest-preemies-2748663>.