

[Twice Born—Stories from the Special Delivery Unit \(2015\), by the Public Broadcasting Service and Trailblazer Studios](#) ^[1]

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In 2015, the Public Broadcasting Service, or PBS, released a three-part documentary series, *Twice Born—Stories from the Special Delivery Unit*, hereafter *Twice Born*, that follows several pregnant women and their experiences with fetal surgery. Trailblazer Studios produced the film, which predominantly features two women, although it includes the stories of many women. The two main women are pregnant with fetuses diagnosed with physical deformities. One woman's [fetus](#) ^[3] is diagnosed with [spina bifida](#) ^[4], an incomplete closure of the fetus's spinal column. The other woman's [fetus](#) ^[3] is diagnosed with an oral [teratoma](#) ^[5], a tumor of the mouth. All the pregnant women in the series went to the Children's Hospital of Philadelphia, or CHOP, in Philadelphia, Pennsylvania, to have *in utero* surgery to correct the fetus's [birth defects](#) ^[6]. *Twice Born* examines the benefits and risks of performing surgery on a [fetus](#) ^[3] still in the pregnant woman's [uterus](#) ^[7]. Due to the popularity of PBS, the documentary reached a wide audience and brought the topic of *in utero* surgery to the public's attention.

In the 1980s, researchers proposed the idea of treating [birth defects](#) ^[6] *in utero*, or while the [fetus](#) ^[3] was still in the [womb](#) ^[8]. According to Nick Scott Adzick, the chief surgeon and director of the Center for Fetal Diagnosis and Treatment at CHOP, skepticism surrounded the idea and at medical conferences, few medical professionals took the proposal of *in utero* surgery seriously. Even with the skepticism, some medical professionals began attempting *in utero* repairs of [birth defects](#) ^[6] like [spina bifida](#) ^[4]. In the early 1980s, Alfred de Lorimier and Michael Harrison, pediatric surgeons at the University of California, San Francisco in San Francisco, California, used an open hysterotomy, or an incision through the pregnant woman's abdomen and into the [uterus](#) ^[7], to repair fetal myelomeningocele, a common form of [spina bifida](#) ^[4]. In 1997, Noel Tulipan, a pediatric neurosurgeon, performed a successful *in utero* repair of [spina bifida](#) ^[4]. Following Tulipan's success, *in utero* surgery became more common, and several hospitals became known for such surgeries.

One such hospital was the Children's Hospital of Philadelphia, where surgeons began performing *in utero* surgeries in 1995. In 2015, over 500 women pregnant with fetuses diagnosed with [birth defects](#) ^[6] went to the Children's Hospital of Philadelphia to be evaluated as possible candidates for the surgery. Before having the surgery, both the pregnant woman and the [fetus](#) ^[3] must undergo testing, such as ultrasounds and magnetic resonance imaging (MRI), to be considered as possible candidates for *in utero* surgery. Once the pregnant woman and [fetus](#) ^[3] have undergone testing, a group of doctors gather to discuss the test results and decide what the best treatment option is. Not all women and fetuses are eligible for *in utero* surgery. Women who are not eligible have the option to terminate their pregnancies or proceed with the [pregnancy](#) ^[9] without *in utero* surgery.

In 2015, PBS produced the documentary series *Twice Born* to explore how a woman gets from a diagnosis of fetal anomaly, to a potential treatment, to giving birth. The series predominantly follows two women pregnant with fetuses diagnosed with birth defects, although the stories of other women are also included. The series is divided into three parts. Part one of *Twice Born* introduces two pregnant women undergoing testing for the possibility of being candidates for *in utero* surgery. Part two of the documentary series continues following both pregnant women from part one as one of the women experiences the aftermath of *in utero* surgery. Concluding the third part of the series, the filmmakers show both women as they prepare to go home from the hospital with their infants after giving birth.

The first part of *Twice Born*, which aired on 31 March 2015, introduces two women pregnant with fetuses diagnosed with [birth defects](#) ^[6]. The first woman, Shelly, appears with her husband, Bobby. In the eighteenth week of her [pregnancy](#) ^[9], Shelly has an [ultrasound](#) ^[10], an imaging technique to produce images of the [fetus](#) ^[3]. After that [ultrasound](#) ^[10], Shelly's physician diagnosed her female [fetus](#) ^[3] with myelomeningocele. The physicians explain that myelomeningocele, the most frequent and severe form of [spina bifida](#) ^[4], is a condition in which the bony spinal column does not develop correctly causing an opening of the spine and exposure of the spinal cord. As a result, a small sac often forms along the spine containing cerebrospinal fluid. According to *Twice Born*, myelomeningocele affects 3.4 infants per 10,000 live birth in the United States. Of those infants affected, ten percent die of myelomeningocele. It can cause paralysis, the inability to control bowel movements, and [hydrocephalus](#) ^[11]. Hydrocephalus consists of an accumulation of too much cerebrospinal fluid in the brain and can cause impaired bladder control, balance problems, and progressive mental impairment.

Shelly explains that pregnant women who have a [fetus](#) ^[3] diagnosed with myelomeningocele are often presented with three treatment options. Those options are terminating the [pregnancy](#) ^[9], having *in utero* surgery to repair the spinal opening, or having postnatal surgery to repair the opening. Postnatal surgery entails surgery on the infant within the first twenty-four to forty-eight

hours after birth. In the documentary, Shelly and her husband detail their decision-making progress after receiving the diagnosis. After learning about the possible treatment options, Shelly, in the nineteenth week of [pregnancy](#)^[9], undergoes the two-day testing process to determine if *in utero* surgery is an option. As part of the testing, Shelly and her [fetus](#)^[3] undergo an MRI to gain information about how the fetus's brain is developing. In addition, her physician performs an [ultrasound](#)^[10] to see where the myelomeningocele sac is located on the [fetus](#)^[3]. Typically, the higher the location of the sac on the fetus's spinal column, the more nerves are affected, which can result in paralysis of the fetus's legs.

Shelly and her husband describe in the series that the test results indicated that Shelly and her [fetus](#)^[3] were not candidates for *in utero* surgery. As they explain, that was because her [fetus](#)^[3] did not have [hindbrain](#)^[12] herniation. Hindbrain herniation occurs when the base of the brain is pulled into the spinal canal and can affect hand coordination and motor skills. Toward the end of part one, Shelly's physicians suggest that Shelly undergo testing again, three to four weeks later, to determine if her [fetus](#)^[3] had developed [hindbrain](#)^[12] herniation. Although it is not mentioned in the documentary, Adzick notes that if a [fetus](#)^[3] has [hindbrain](#)^[12] herniation, once the infant is born, it will have to have many post-natal surgeries to correct the condition. Therefore, if a [fetus](#)^[3] has [hindbrain](#)^[12] herniation in the [womb](#)^[8], surgeons will perform *in utero* surgery to correct it earlier and prevent the post-natal surgeries. As the documentary continues, Lesly and her [fetus](#)^[3] are introduced.

Twenty-one year old Lesly found out that her [fetus](#)^[3] was diagnosed with an oral [teratoma](#)^[5]. An oral [teratoma](#)^[5] is a mass of abnormal cells that can consist of hair, teeth, muscle, fat, nerve tissue, and bones that resemble other bones in the human body. The large mass in the mouth can block the fetus's airway. As detailed in the documentary, Lesly was given two treatment options, to terminate the [pregnancy](#)^[9] or to undergo an *in utero* surgery.

In the first part of the PBS series, Lesly chooses *in utero* surgery as the treatment option for the [fetus](#)^[3] and underwent the procedure. The *in utero* surgery for the treatment of oral [teratoma](#)^[5] is called an exit procedure. During an exit procedure, a surgeon delivers the head and arms of the [fetus](#)^[3] to establish an airway prior to cutting the [umbilical cord](#)^[13] between the [fetus](#)^[3] and the mother. As part of the documentary, Holly Hedrick, an attending pediatric and fetal surgeon at CHOP, performs the exit procedure on Lesly. Hedrick makes an incision in Lesly's lower abdomen and then delivers the fetus's head and arms through the incision. Once the [fetus](#)^[3] is partially delivered, Hedrick works to establish an airway. However, the airway was too small and she had to perform a tracheotomy, an incision in the windpipe. After completing the tracheotomy, Hedrick delivers the [fetus](#)^[3] and removes more than half of the mass from the infant's mouth. As part one of *Twice Born* concludes, Lesly sees her infant for the first time.

Part two of *Twice Born* aired on 7 April 2015, and continues with Shelly's story. Shelly has undergone another MRI showing that [hindbrain](#)^[12] herniation was present in her [fetus](#)^[3]. Therefore, Shelly and her [fetus](#)^[3] are candidates for *in utero* surgery. Prior to undergoing the surgical procedure, Shelly has to acknowledge the benefits and risks of the surgery, which are explained to her during the documentary. According to the series, the benefits of *in utero* surgery include improved motor function, specifically in the legs, and the increased ability to walk by the age of two. Along with the benefits of the surgery, the show details the main risk of *in utero* surgery, premature birth. Premature infants have a lower chance of survival due to their underdeveloped lungs. In the documentary, Shelly accepts the benefits and risks of the *in utero* surgery and proceeds with the procedure.

In the middle of the second part of *Twice Born*, Shelly, twenty-two weeks into her [pregnancy](#)^[9], undergoes *in utero* surgery. Adzick leads the procedure along with a team of specialists. Adzick puts Shelly under anesthesia and makes an incision in her abdomen to expose her [uterus](#)^[7]. Once Shelly's [uterus](#)^[7] is exposed, Adzick determines the best place for a uterine incision with an [ultrasound](#)^[10]. The best place to make an incision is where there are no fetal parts, [umbilical cord](#)^[13], or [placenta](#)^[14], which cutting could result in injury to the [fetus](#)^[3]. After Adzick makes an incision in the [uterus](#)^[7], a neurosurgeon repairs the fetus's exposed spinal column. Once the neurosurgeon is finished, Adzick sutures Shelly's [uterus](#)^[7] back together, leaving the [fetus](#)^[3] inside the [womb](#)^[8].

In part two of the series, the series introduces Tina and her husband, Brion. Seventeen weeks into her [pregnancy](#)^[9], Tina receives her first [ultrasound](#)^[10] and finds out she is having twins that were diagnosed with twin to twin transfusion syndrome. Twin to twin transfusion syndrome is a birth defect that occurs among identical twins who share one [placenta](#)^[14]. In twin to twin transfusion syndrome, abnormal blood vessels form in the placental and result in an uneven distribution of blood between twins. As a result, one twin receives less blood and becomes dehydrated and the other twin receives too much blood and develops high blood pressure. In the documentary, Tina undergoes another [ultrasound](#)^[10]. In the [ultrasound](#)^[10], Tina and Brion learn that the twin fetuses have died due to twin to twin transfusion syndrome. Four days after the [ultrasound](#)^[10], Tina gives birth to the deceased twin girls. As the second part of the documentary continues, Lesly awaits her infant's surgery.

In continuation of part two of the documentary, the show focuses on Lesly's infant, Lilly, who was awaiting surgery to remove the rest of her tumor. Lesly and Luv Javia, an attending physician with the Division of Otolaryngology at CHOP, discuss the next steps of Lilly undergoing surgery to remove the remnants of the tumor from her mouth. Javia performs surgery on Lilly and successfully removes the rest of the tumor from her mouth. Due to the success of the surgery, Lilly has full use and function of her tongue. As part two of the series comes to an end, Lilly goes home with Lesly for the first time after being in the hospital for four months. The final part of *Twice Born* entails Lilly embarking on another surgery and Shelly giving birth to a female infant.

On 14 April 2015, the final part of *Twice Born* aired, and in it Shelly gives birth to Luelle at thirty-six weeks and six days' [gestation](#)^[11]

^[15]. In the documentary, physicians [ultrasound](#) ^[10] Luelle's head to detect for [hydrocephalus](#) ^[11]. They find that the size of the fluid-filled cavities, or ventricles, in Luelle's brain have increased and they diagnose her with [hydrocephalus](#) ^[11]. In addition to the [ultrasound](#) ^[10], a neuropsychologist examines her to see if she is meeting cognitive milestones for her age group. After the exam, the neuropsychologist concludes that because of the myelomeningocele, Luelle is behind in verbal and speech development. Following the conclusions of the neuropsychologist, Benjamin Warf, professor of Neurosurgery at [Harvard Medical School](#) ^[16] in Boston, Massachusetts, gives Luelle an MRI. From the MRI, Warf concludes that Luelle's ventricles had shrunk and she would not have to have brain surgery. As the show concludes on Luelle, Geneva and Reggie are introduced.

In the middle of the third episode, Geneva and her husband, Reggie, are introduced as they learn that their [fetus](#) ^[3] was diagnosed with a fetal urinary tract obstruction. A fetal urinary tract obstruction stops the flow of urine in the [fetus](#) ^[3]. When the urine flow stops in the [fetus](#) ^[3], it can cause an enlarged bladder, enlarged kidneys, and possibly death. Geneva receives an [ultrasound](#) ^[10] to see how the fetal urinary tract obstruction is affecting her [fetus](#) ^[3]. The [ultrasound](#) ^[10] shows the [fetus](#) ^[3] is suffering from an enlarged bladder, more than double the size of a normal bladder, and enlarged kidneys. Physicians present two treatment options to Geneva and Reggie, to terminate the [pregnancy](#) ^[9] or to undergo *in utero* surgery. In the series, Geneva and Reggie decide to proceed with *in utero* surgery. Prior to obtaining the surgery, Geneva undergoes an additional [ultrasound](#) ^[10] to view how the fetal urinary tract obstruction is progressing. The results of the [ultrasound](#) ^[10] show that the [fetus](#) ^[3] has started to pass urine again, indicating *in utero* surgery is no longer required. As the documentary nears its end, Geneva gives birth to her son, Ricky. After birth, Ricky undergoes a minor surgery for urinary obstruction. As the show concludes its story on Ricky, it returns to Lilly, who is awaiting plastic surgery on her lip.

The last part of *Twice Born* shows Lilly receiving plastic surgery to close the left side of her lip. Due to the large tumor, the left side of Lilly's lip is stretched and the resulting excess skin is removed during the surgery. During the procedure, Javia inserts a camera through Lilly's mouth to her windpipe to look at the tracheotomy that was performed at birth. Javia's goal is to close Lilly's tracheotomy, but Lilly's airway is too small and the tracheotomy has to be left in place. As the documentary ends, Lilly can successfully eat and drink on her own.

Twice Born, the three-part documentary series, acknowledged the benefits and risk of *in utero* procedures. On 21 September 2016, PBS was awarded the Outstanding Science and Technology Programming Emmy. As of 2017, more than 1200 fetal surgeries have been performed at CHOP since 1995 and a fetal family reunion is held every summer for the families.

Sources

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Subject

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