Utah Department of Health & Human Services

July 2024

Utah health status update

Key findings

- The Utah mandate to require pulse oximetry screening of newborns for critical congenital heart disease (CCHD) has significantly increased the number of infants screened since its implementation in 2014.
- While pulse oximetry is a useful diagnostic tool, it has limited sensitivity leading to some missed cases of CCHD.
- Certain circumstances, such as prenatal indication of CCHD, result in healthcare staff opting to perform an echocardiogram in place of pulse oximetry screening after birth.
- Newborns with a failed pulse oximetry screen who were diagnosed with CCHD received follow-up care for enhanced CCHD intervention and resources.

Screening and diagnosis of critical congenital heart disease in Utah, 2018–2022

Critical congenital heart diseases (CCHD) are the most severe types of congenital heart defects and can result in serious, life-threatening symptoms. Approximately 1 in 451 infants in Utah are born with a CCHD.[1] While CCHDs usually require intervention, CCHDs are often treatable if detected early.

Newborn heart screening is recommended soon after birth to identify and prevent significant morbidity and mortality from CCHD which can be detected through multiple approaches. The most common is pulse oximetry, which is a quick, safe, and painless screening tool that measures the amount of oxygen in the blood. Pulse oximetry identifies newborns who have low oxygen levels, the most common sign of CCHD. It is recommended that birth providers and facilities follow the pulse oximetry screening protocol endorsed by the American Academy of Pediatrics, which states CCHD screening should be performed within the first 2 days of life or before discharge from a hospital or birth center.[2] Newborns with a failed pulse oximetry screening or prenatal indication of CCHD are recommended to have an echocardiogram performed. Echocardiogram is a more complex and extensive test that is used for further evaluation when CCHD is suspected.

On October 1, 2014, newborn heart screening by pulse oximetry was mandated in Utah and screening results are required to be reported to the CCHD Screening Program within the Utah Birth Defect Network (26B-4-319. Testing of newborn infants and Birth Defects and Critical Congenital Heart Disease Reporting Rule R398-5). Since 2014, there has been considerable improvement in the number of newborns who are screened for CCHD using pulse oximetry. In 2022, 96.5% of all babies born in Utah were screened after birth as compared to 92.4% in 2015 (Figure 1).

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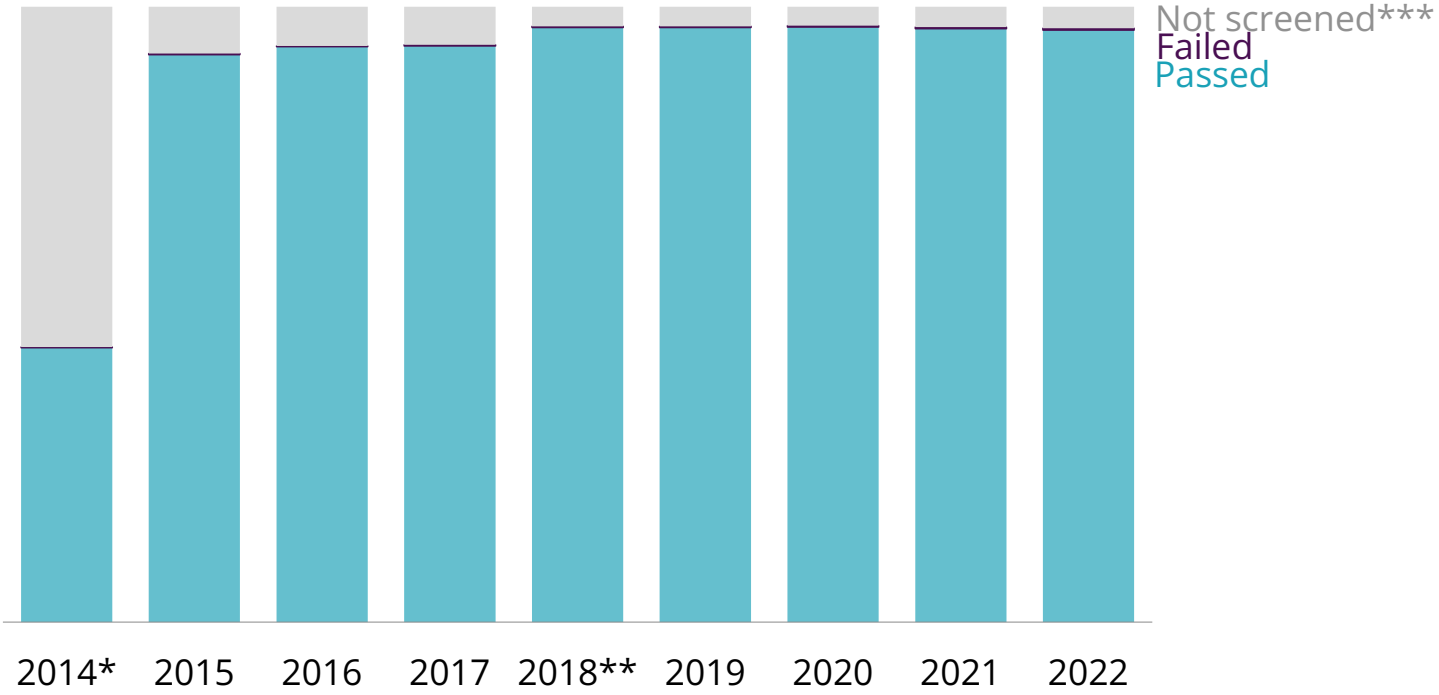
Feature article continued

Utah CCHD pulse oximetry screening results by birth year, 2014–2022

Figure 1. The percentage of newborns screened using pulse oximetry in Utah increased after the mandate in October of 2014..



* CCHD pulse oximetry screening mandated October 1, 2014
** CCHD Screening Program begins reviewing all "not screened" cases
*** "Not screened" includes invants who received an echocardiogram performed in place of pulse oximetry, the newborns who were deceased/ received palliative care, family refused, or other.
Sources: CCHD Screening Program, Utah Birth Defect Network, Utah Department of Health and Human Services; Office of Vital Records and Statistics, Utah Department of Health and Human Services

While there has been significant improvement in the percentage of newborns screened for CCHD since 2014, monitoring and evaluation of screening numbers are important to identify gaps in screening procedures and to make sure newborns with an abnormal screen receive necessary follow-up care.

Pulse oximetry screening is most useful to identify CCHD that has not already been identified during prenatal screening. Most infants with CCHD born in Utah between 2018 and 2022 were diagnosed before birth (57%), therefore pulse oximetry was not of high value (Table 1). While pulse oximetry is of high value for those infants who were not diagnosed with CCHD prenatally, there were low rates of pulse oximetry screening among newborns who were diagnosed with CCHD during delivery hospitalization (30%) due to concerning clinical indicators that resulted in an echocardiogram being performed instead.

While pulse oximetry is a useful diagnostic tool, it has limited sensitivity leading to some missed cases of CCHD. Pulse oximetry missed CCHD in 44% of newborns diagnosed during delivery hospitalization and in 98.2% of newborns diagnosed after discharge (Table 1). The most common diagnoses related to false negative CCHD screens include coarctation of the aorta and tetralogy of Fallot (TOF), 2 complex heart conditions. This is consistent with other findings.[3] This highlights the importance of a thorough examination of newborns for CCHD indication in tandem with pulse oximetry screening.

Feature article continued

Newborns with a failed pulse oximetry screening or prenatally suspected CCHD are recommended to have an echocardiogram performed. Regardless of the timing of diagnosis, 95% of all infants with diagnosed CCHD received an echocardiogram either pre- or postnatally. Among prenatally indicated CCHD cases, 91.8% of cases received an echocardiogram after birth in place of pulse oximetry screening. Nearly all newborns diagnosed with CCHD during delivery hospitalization (99%) or after discharge (98%) had an echocardiogram performed (Table 1). Reasons for not receiving an echocardiogram include a family deciding to pursue palliative care or the newborn died shortly after birth.

Timing of critical congenital heart disease (CCHD) diagnosis and selected characteristics, 2018–2022

Table 1. Most infants were diagnosed with CCHD prior to birth (57%). An additional 30% were diagnosed during delivery hospitalization, and 12% had diagnosis after discharge.

	Prenatal diagnosis	Diagnosis during delivery hospitalization	Diagnosis after discharge
Percent of infants with CCHD by diagnosis time	57%	30%	12%
Delivery location			
Home	0%	3.4%	0%
Hospital	100%	95.3%	100%
Other (e.g., birthing centers)	0%	1.3%	0%
Infants with CCHD with missed diagnosis from pulse oximetry*	0.4%	44%	98.2%
Infants with CCHD that did not receive appropriate screening**	0%	0%	1.8%
Received an echocardiogram	91.8%	99%	98%

* if received pulse oximetry
** Not screened by pulse oximetry or echocardiogram
Sources: CCHD Screening Program, Utah Birth Defect Network, Utah Department of Health and Human Services; Office of Vital Records and Statistics, Utah Department of Health and Human Services

All newborns diagnosed with CCHD with a failed screen received an echocardiogram (100%), 75% were admitted to a Level III or Level IV neonatal intensive care unit (NICU), and 71% were transferred to another hospital with higher level of care. All CCHD-diagnosed newborns with a failed pulse oximetry screening in an out-of-hospital setting were admitted to a hospital within 72 hours (100%) (Table 2).

For additional information on screening for CCHD, visit familyhealth.utah.gov/cshcn/cchd/.

Recommendations

- Provide education to healthcare staff, midwives, and other birthing staff on the importance of newborn heart screening and other CCHD indicators, as well as coordination to follow-up care if needed.
- Provide out-of-hospital birthing staff with the necessary information and resources to connect families with suspected CCHD to additional medical resources. The CCHD Screening Program is working with the DHHS Office of Maternal and Child Health to develop a CCHD Screening Transfer Form for midwives if CCHD is suspected through a failed screen or other concerning indicators.

Feature article continued

Selected characteristics of newborns with a failed pulse oximetry screening, Utah, 2018–2022

Table 2. A high percentage of newborns with a failed screen were connected with follow-up care, regardless of delivery or screening location.

	% of newborns diagnosed with CCHD with a failed screen
Delivery location	
Home	3.6%
Hospital	92.8%
Other (e.g., birthing centers)	3.6%
CCHD screen location	
Home	7.1%
NICU/PICU/CICI/Level 2	7.1%
Well baby (newborn) nursery	85.8%
Admit to hospital within 72 hours if out of hospital birth	100%
Admitted to Level III/IV NICU	75%
Transferred to another hospital	71%
Received an echocardiogram	100%

Sources: CCHD Screening Program, Utah Birth Defect Network, Utah Department of Health and Human Services; Office of Vital Records and Statistics, Utah Department of Health and Human Services

1. CCHD Screening Program, Utah Birth Defect Network, Utah Department of Health and Human Services.

2. Kemper, A. R., Mahle, W. T., Martin, G. R., Cooley, W. C., Kumar, P., Morrow, W. R., ... & Howell, R. R. (2011). Strategies for implementing screening for critical congenital heart disease. Pediatrics, 128(5), e1259–e1267.

3. Ailes, E. C., Gilboa, S. M., Honein, M. A., & Oster, M. E. (2015). Estimated number of infants detected and missed by critical congenital heart defect screening. Pediatrics, 135(6), 1000–1008.

Spotlights

Utah Department of Health & Human Services

July 2024

Traumatic injuries in Utah: By the numbers

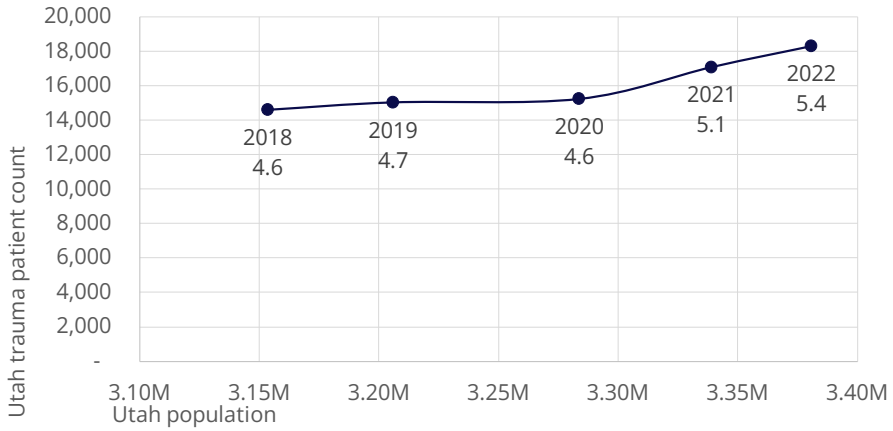
Introduction

Traumatic injury, defined as a body wound caused by a force impact from an unintentional or intentional source, is the leading cause of preventable fatality and disability among Americans aged 1 to 44 years. Each year, more than 140,000 people die and approximately 80,000 are permanently disabled due to traumatic injuries in the United States. In the past 20 years, the Utah Trauma Registry (UTR) has collected traumatic injury data from all hospitals in the state to create an effective trauma system and reduce unnecessary fatalities and morbidity from injuries. A recently published report highlights findings from UTR data covering the years 2018 to 2022.

Population growth and traumatic injury incidence

The number of traumatic injuries is increasing at a faster rate than the increase in the population. Utah's population grew from 3,153,550 in 2018 to 3,380,800 in 2022, a 7% increase. The incidence of traumatic injuries increased from 4.6 per 1,000 residents in 2018 to 5.4 in 2022, a 17% increase (Figure 1).

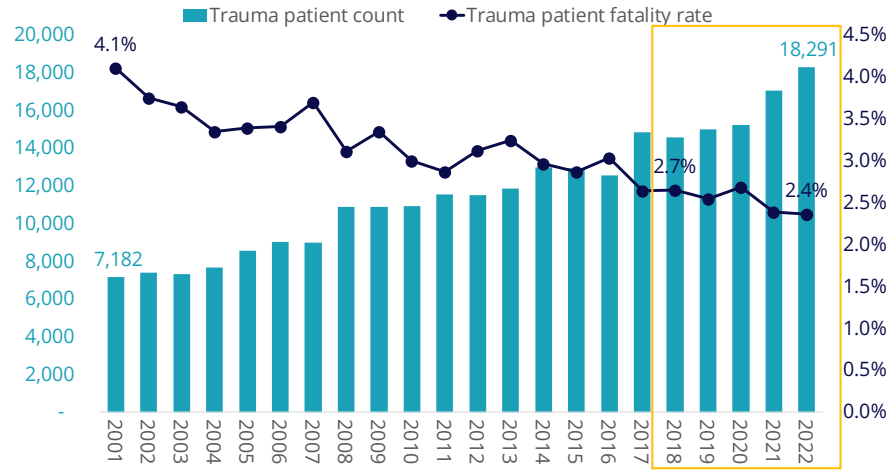
Figure 1. 2018–2022 Utah population and traumatic injury incidents per 1,000



Sources: Utah Trauma Registry; U.S. Census Bureau, Population Division

Despite the rising number of trauma patients, the statewide trauma fatality rate has been steadily decreasing, dropping from 4.1% to 2.7% between 2001 and 2018, and further to 2.4% between 2018 and 2022, showing Utah's trauma system has improved in the past years (Figure 2).

Figure 2. Number of trauma patients and fatality rate, Utah, 2018–2022



Source: Utah Trauma Registry

Age groups and demographics

Although individuals aged 65 and older constituted only 12% of the population in Utah (Census Bureau estimates), they represented 41% of trauma cases recorded in the UTR. Pediatric patients (aged 0–14) made up 24% of the population but only 12% of trauma cases. Adult patients (aged 15–64) accounted for 65% of the population and 48% of trauma cases (Figure 3).

The geriatric population traumatic injury rate decreased to 15.8 per 1,000 in 2020 and this population experienced a reduction in trauma fatality shifting from 0.56 per 1,000 in 2018 to 0.45 in 2022 (Figure 4). However, pediatric traumatic injury increased during the pandemic and pediatric fatality slightly increased from 0.02 per 1,000 to 0.04 toward the end of the pandemic (Figure 5). Gunshot

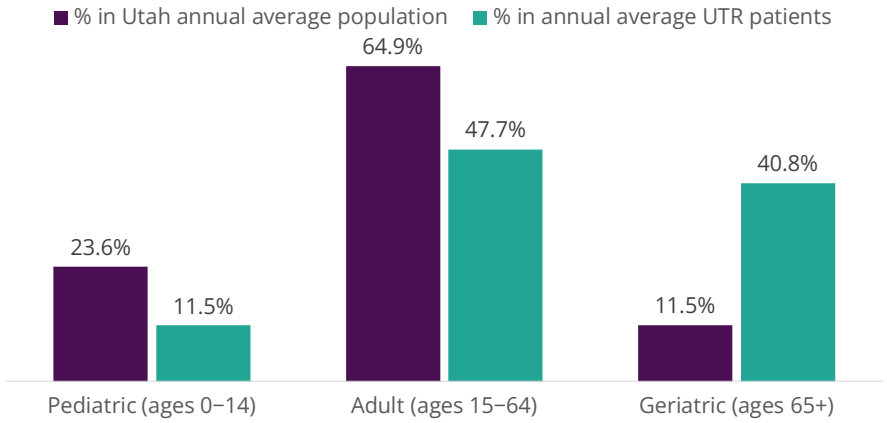
wounds (including both intentional and unintentional) and assaults (including child abuse) were the leading causes of pediatric fatality. Several reports[1,2] suggest that although child abuse reporting decreased during the pandemic, unreported child abuse cases may have contributed to the increase in pediatric traumatic injuries. This was not discernable in the improving statewide traumatic injury fatality rate, due to the overrepresentation of the geriatric population and underrepresentation of the pediatric population in the trauma registry (Figure 3). Planning traumatic injury prevention and intervention strategies for the pediatric population is warranted for future pandemic situations.

For information about preventing injury, see the DHHS Violence and Injury Prevention and Healthy Aging Programs' websites.

1. Pediatric Trauma More Common During COVID-19 Pandemic, Especially for Children in Disadvantaged Neighborhoods. American College of Surgeons. October 20, 2023. https://www.facs.org/for-medical-professionals/conferences-and-meetings/clinical-congress-2023/media/kit/pediatric-trauma-more-common-during-covid-19-pandemic-especially-for-children-in-disadvantaged-neighborhoods/

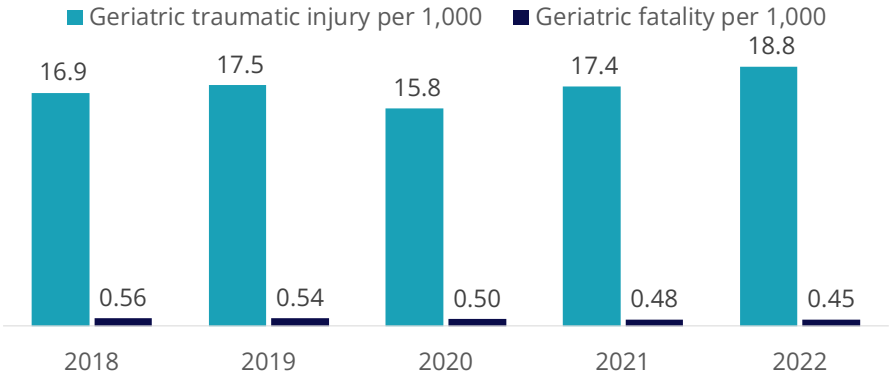
2. National Statistics on Child Abuse. National Children's Alliance. https://www.nationalchildrensalliance.org/media-room/national-statistics-on-child-abuse/

Figure 3. Average annual Utah population and trauma patients by age group, 2018–2022



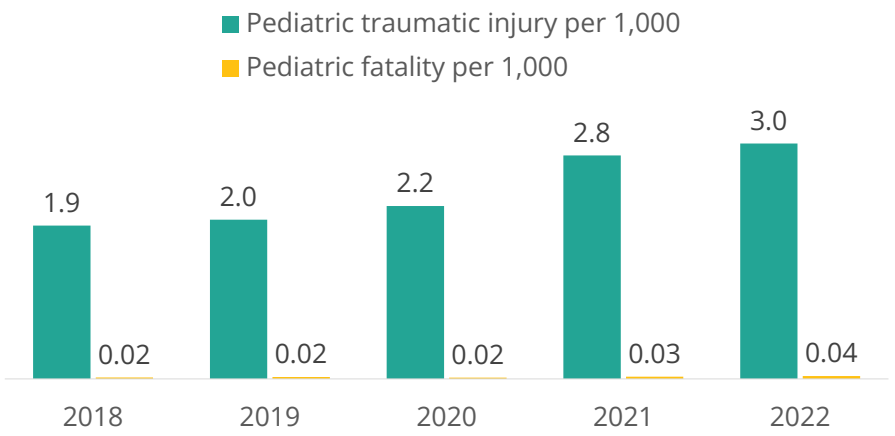
Sources: Utah Trauma Registry; U.S. Census Bureau, Population Division

Figure 4. Geriatric traumatic injury incidents and fatalities per 1,000 population by year, Utah, 2018–2022



Source: Utah Trauma Registry; U.S. Census Bureau, Population Division

Figure 5. Pediatric traumatic injury incidents and fatalities per 1,000 population by year, Utah, 2018–2022



Source: Utah Trauma Registry; U.S. Census Bureau, Population Division

Spotlights

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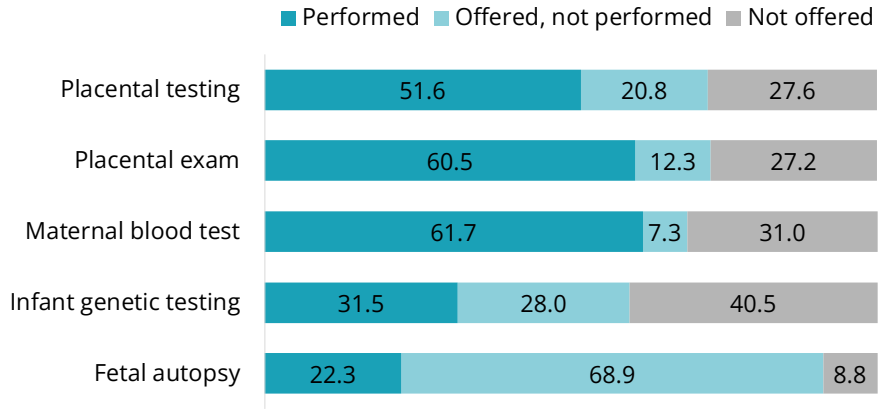
Autopsy and diagnostic testing procedures following stillbirth: findings from the Utah SOARS survey (2018–2021)

Stillbirth is when a baby dies in the womb after 20 weeks of gestation, and can cause long-lasting psychological impacts on parents, families, and communities. There were 251 stillbirths in Utah in 2022. Determining the cause of a stillbirth can be difficult in many cases but informs prevention efforts, which is why fetal autopsies and other testing procedures are recommended to be offered to families. The American College of Obstetricians and Gynecologists recommends a pathologist perform a detailed examination of the placenta for all stillbirth evaluations, and other diagnostic procedures such as maternal blood testing and infant genetic testing are recommended on a case-by-case basis.[1] Despite these recommendations, many families are not offered these services.

The Study of Associated Risks of Stillbirth (SOARS) is a survey project of the Utah Department of Health and Human Services and Centers for Disease Control and Prevention (CDC). SOARS is an ongoing, state-specific, population-based survey designed to collect information on maternal experiences and behaviors before, during, and immediately following pregnancy among mothers who have recently experienced a stillbirth. The current dataset contains information on stillbirths that occurred to Utah mothers from June 2018 through December 2021.

Among SOARS respondents, 8.8% said they were not offered a fetal autopsy, 27.2% were not offered a placental exam, and 7.7% were not offered any diagnostic testing procedures. Written responses also indicate lack of information as a factor for not having an autopsy performed, with one mother stating, "I did not understand what would be done to my baby's body. If I understood more about the process I may have asked for an autopsy."

Percentage distribution of fetal testing offered and/or performed during hospital stay (%), Utah, 2018–2021



Source: Utah SOARS survey

Improving both patient and provider knowledge about the process and benefits of a comprehensive stillbirth evaluation could be key to improving stillbirth diagnostic testing rates. Determining the cause of the stillbirth may also aid in the bereavement process and assist in future family planning decisions.[2] The University of Utah Department of Obstetrics and Gynecology offers a number of stillbirth services, including in-depth patient consultations with specialized physicians. These consultations can assist families in identifying the cause of the stillbirth and provide recommendations for future pregnancies. The University of Utah offers training for health care providers and conducts research studies to better understand stillbirth and fetal loss. More information on these services can be found at https://medicine.utah.edu/obgyn/research/stillbirth.

Earlier this year, the Utah Pregnancy After Loss Program launched, which provides customized care to pregnant or planning to be pregnant patients who have experienced pregnancy loss, newborn death, or severely complicated pregnancy. Information on this program can be found at https://healthcare.utah.edu/womens-health/pregnancy-birth/pregnancy-after-loss.

1. Management of stillbirth. ACOG. March 2020. Accessed June 11, 2024. https://www.acog.org/clinical/clinical-guidance/obstetric-care-consensus/articles/2020/03/management-of-stillbirth

2. Horey D, Flenady V, Conway L, McLeod E, Yee Khong T. Decision influences and aftermath: parents, stillbirth and autopsy. Health Expect. 2014;17(4):534-544. doi:10.1111/j.1369-7625.2012.00782.x