The Texas Birth Defects MONITOR

An Annual Data and Research Update

Texas Birth Defects Epidemiology and Surveillance

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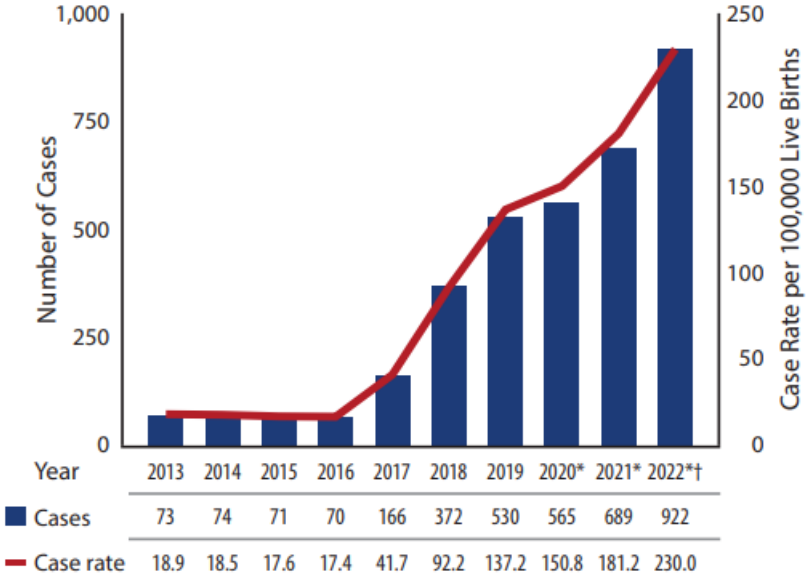
Collaboration to Combat Congenital Syphilis in Texas

Congenital Syphilis is caused by transmission of the bacterium, spirochete Treponema pallidum, from mother to fetus. Pregnant women can pass syphilis to their unborn children during pregnancy or at delivery when they are not treated or inadequately treated. A syphilis diagnosis during pregnancy increases adverse pregnancy outcomes, including miscarriage, stillbirth, preterm birth, birth defects, and/or perinatal death. Rates for congenital syphilis are on the rise nationally and in Texas.

Historically, Texas has reported high rates of syphilis compared to other states. From 2018 to 2022, congenital syphilis has increased by approximately 148 percent. In 2022, Texas reported 1,131 cases of primary and secondary syphilis (symptomatic syphilis) among women of childbearing age at a rate of 18.0 per 100,000 females. Similarly, Texas reported 922 cases of congenital syphilis in 2022 with a rate of 230.0 per 100,000 births (Figure 1).

Figure 1: Texas Congenital Syphilis Cases and Rates by Year of Diagnosis, 2013-2022



Year	2013	2014	2015	2016	2017	2018	2019	2020*	2021*	2022*†
Cases	73	74	71	70	166	372	530	565	689	922
Case rate	18.9	18.5	17.6	17.4	41.7	92.2	137.2	150.8	181.2	230.0

*2020-2022 congenital syphilis case rates based on provisional 2020-2022 birth data.
†2022 data are provisional.

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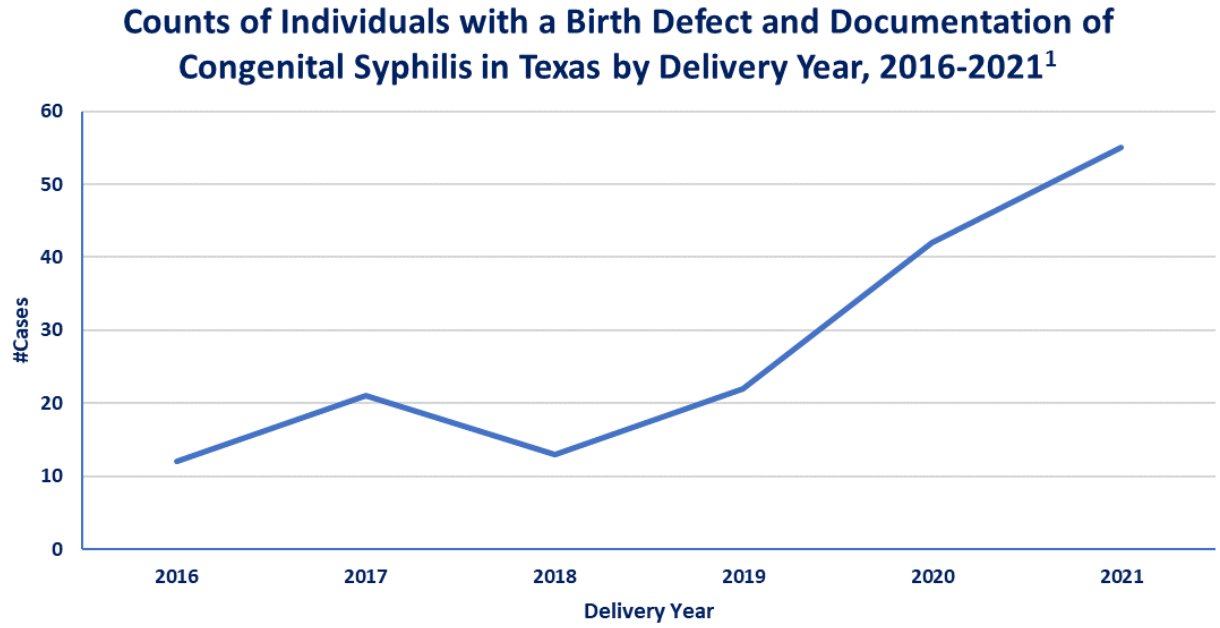
The Texas Birth Defects Registry (TBDR) and HIV/STD programs established a data use agreement, allowing the TBDR to share congenital syphilis cases for quarterly case finding. This collaboration aims to provide a supplementary source of data for affected babies, identify risk factors for prevention, evaluate birth defects secondary to syphilis infection, and enable bidirectional feedback for refined epidemiological analysis.

Congenital syphilis is conditionally included in the TBDR. This means it is recorded only when individuals have a reportable birth defect and a positive congenital syphilis laboratory report or when medical records report both 'congenital syphilis' and a reportable birth defect.

To date, the TBDR has reported 179 individuals with an indication of congenital syphilis to the HIV/STD program. The number of cases reported to HIV/STD has been increasing with time. In 2021, over 50 individuals were identified with congenital syphilis and a birth defect (Figure 2).



[1] Delivery Years 2020-2021 are provisional data.

Information provided to the HIV/STD program includes identifiers, medical record numbers, facility identifiers, demographics, birth defects, and all prenatal and postnatal results. Analysis of TBDR data reveals that the congenital syphilis diagnosis is primarily found in the postnatal procedures performed in response to suspected congenital syphilis. These postnatal procedures include radiography, infectious disease consultations, and auditory brainstem response tests among others.

Analysis of the TBDR's data for years 2012-2019, reveals that the only statistically significant elevated birth defect among individuals with confirmed congenital syphilis was severe microcephaly (head circumference <3rd percentile for gestational age and sex). In Texas, there was a seven-fold increase of severe microcephaly among infants or fetuses with a concurrent confirmed congenital syphilis diagnosis with a prevalence of 49.02/10,000 live births (95% confidence interval: 19.71-101.00) (Figure 3).

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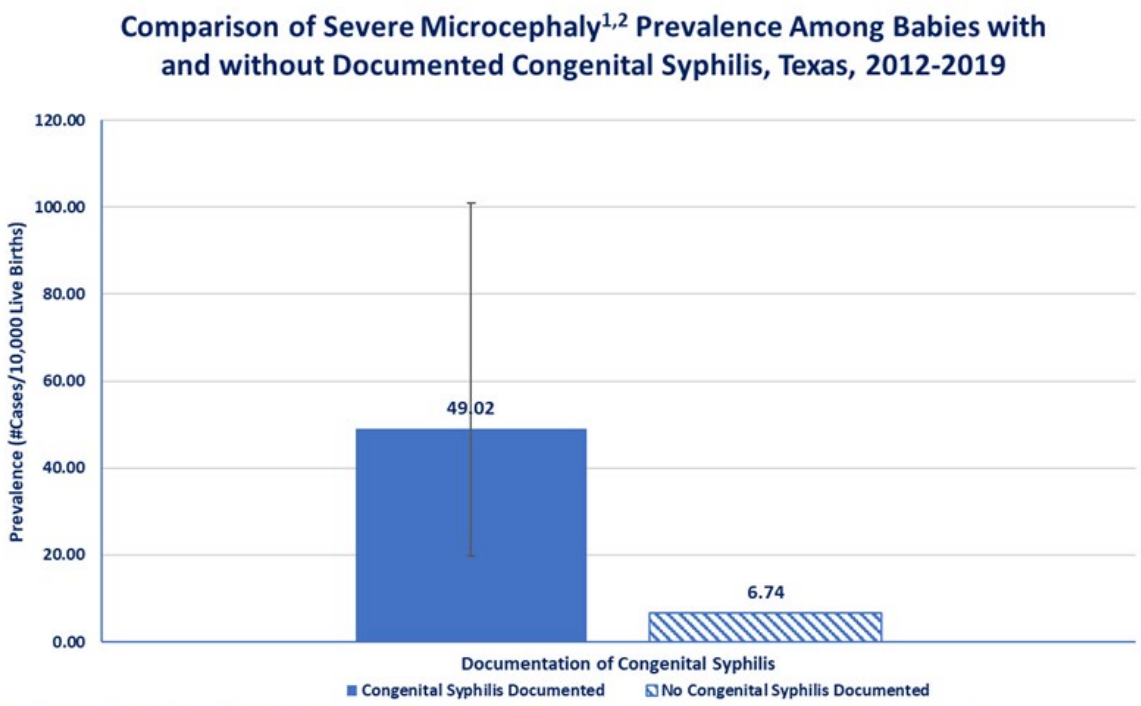

[1]Severe microcephaly is a brain reduction defect where the delivery head circumference is <3rd percentile for gestational age and sex.
[2]Congenital syphilis population as derived from the 2021 Congenital Syphilis Report in Texas, Data for Figure 1
https://www.dshs.texas.gov/sites/default/files/legislative/2020-Reports/2021-Congenital-Syphilis-Report.pdf, (Rev. 4/2021). Accessed 6/29/2023.

The HIV/STD program provided feedback on the 179 individuals for case finding that the TBDR provided. Based on the medical records abstracted by the TBDR: 146 had a definite and 33 a possible/probable diagnostic certainty of congenital syphilis.

The HIV/STD program only identified 4/179 (2.2%) as confirmed cases of congenital syphilis. The majority (n=106, 59.2%) of cases sent to HIV/STD were designated as probable congenital syphilis cases. Finally, 42 (23.5%) were ruled-out as a definite case of congenital syphilis by the HIV/STD program.

The reason for this is that the HIV/STD program utilizes a different case definition for a definite congenital syphilis diagnosis (i.e., spirochetes confirmed) than the TBDR. Lastly, only 4/179 (2.2%) cases were not identified by the HIV/STD program.

This collaborative effort underscores Texas' commitment to address congenital syphilis through legislative measures, data sharing, and ongoing analysis. The partnership between the TBDR and HIV/STD programs aims to enhance understanding, prevention, and intervention in congenital syphilis cases, with implications for policy and public health decision-making.

FYI: Requirements for Congenital Syphilis Screening in Texas

Texas Health and Safety Code Section 81.090, as of 09/01/2023, mandates screenings at the first prenatal visit, third trimester prenatal visit, and delivery, with follow-up screenings for babies with reactive nontreponemal tests whose titers do not decrease to be monitored for up to 18 months and assessment for possible neurosyphilis.

In 2015, Texas instituted Fetal Infant Morbidity Review (FIMR) Boards, to review medical records for fetal/infant deaths and identify community action items. Texas uses FIMR methodology to conduct enhanced reviews of congenital syphilis cases in Houston, San Antonio, and Dallas.

Branch Introduces New Lead Surveillance Specialist Positions

In 2023, the Birth Defects Epidemiology and Surveillance Branch (BDESB) implemented a significant change by introducing the Lead Surveillance Specialist position. This involved upgrading vacant Public Health and Prevention Specialist III roles to Public Health and Prevention Specialist IV positions, now referred to as Lead Surveillance Specialists.

The decision to reclassify positions was driven by evolving business needs. The Lead Surveillance Specialist role is tailored to meet the specific demands of the BDESB. Key responsibilities include active birth defects surveillance, acting as a liaison between specialists and healthcare facilities, and ensuring connectivity to electronic medical record systems.

The Lead Surveillance Specialist will play a pivotal role by conducting various surveillance activities, maintaining relationships with healthcare facilities, and collaborating with IT staff for technological improvements. This includes participation in the Interoperability Workgroup to explore new technologies, serving as a point of contact for regional surveillance staff, and contributing to training and mentoring initiatives.

The reclassification from Public Health and Prevention Specialist III to IV was not just an organizational change; it aimed to enhance employee retention, aligning with agency priorities. By recognizing the evolving demands of the position and upgrading accordingly, the Branch anticipates improved staff satisfaction and commitment.

The introduction of the Lead Surveillance Specialist position reflects the Branch's commitment to adapting to evolving needs. This strategic move not only addresses the technical requirements of surveillance but also emphasizes the importance of employee retention in achieving overall agency goals.

Survival of Infants and Children with Birth Defects: Insights from the Texas Birth Defects Registry

Birth defects affect 3% to 5% of pregnancies and they remain a major cause of infant mortality in the U.S. In a recent study, led by Dr. Renata Benjamin at the University of Texas School of Public Health using Texas Birth Defects Registry (TBDR) data, researchers provided a comprehensive analysis of survival outcomes among infants with major birth defects.

Researchers used data from the TBDR from 1999 to 2017and analyzed survival probabilities for infants with any major defect and 30 specific defects. Factors like gestational age, birth year, and case classification (e.g., an isolated defect versus a syndrome), were considered in the analysis.

Among 246,394 infants born with any major defects, the estimated survival rates were:

- 98.9% at 1 day,
- 95.0% at 1 year, and
- 93.9% at 10 years.

Survival varied by defect type (e.g., 36.9% for holoprosencephaly to 99.3% for pyloric stenosis), gestational age (e.g., preterm infants had lower survival rates), birth year (e.g., one-year survival increased in recent years for specific defects), and case classification (e.g., infants with isolated defects had higher survival).

This study, using data from one of the world's largest birth defect registries, provides information for healthcare professionals, parents, and policymakers. The findings emphasize the importance of considering gestational age and case classification and highlight the impact of recent advances in medical practices and the need for ongoing efforts to reduce mortality among individuals affected by a birth defect.

This study contributes key information for parents, clinicians, and healthcare teams. By focusing on factors like gestational age, the public health community can work towards improving health outcomes for infants with birth defects.

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Figure 1: One-year Kaplan–Meier survival estimates by gestational age at birth, Texas Birth Defects Registry, 1999–2017 births. (Cochran-Armitage trend test p<0.05 for all defect categories shown.)

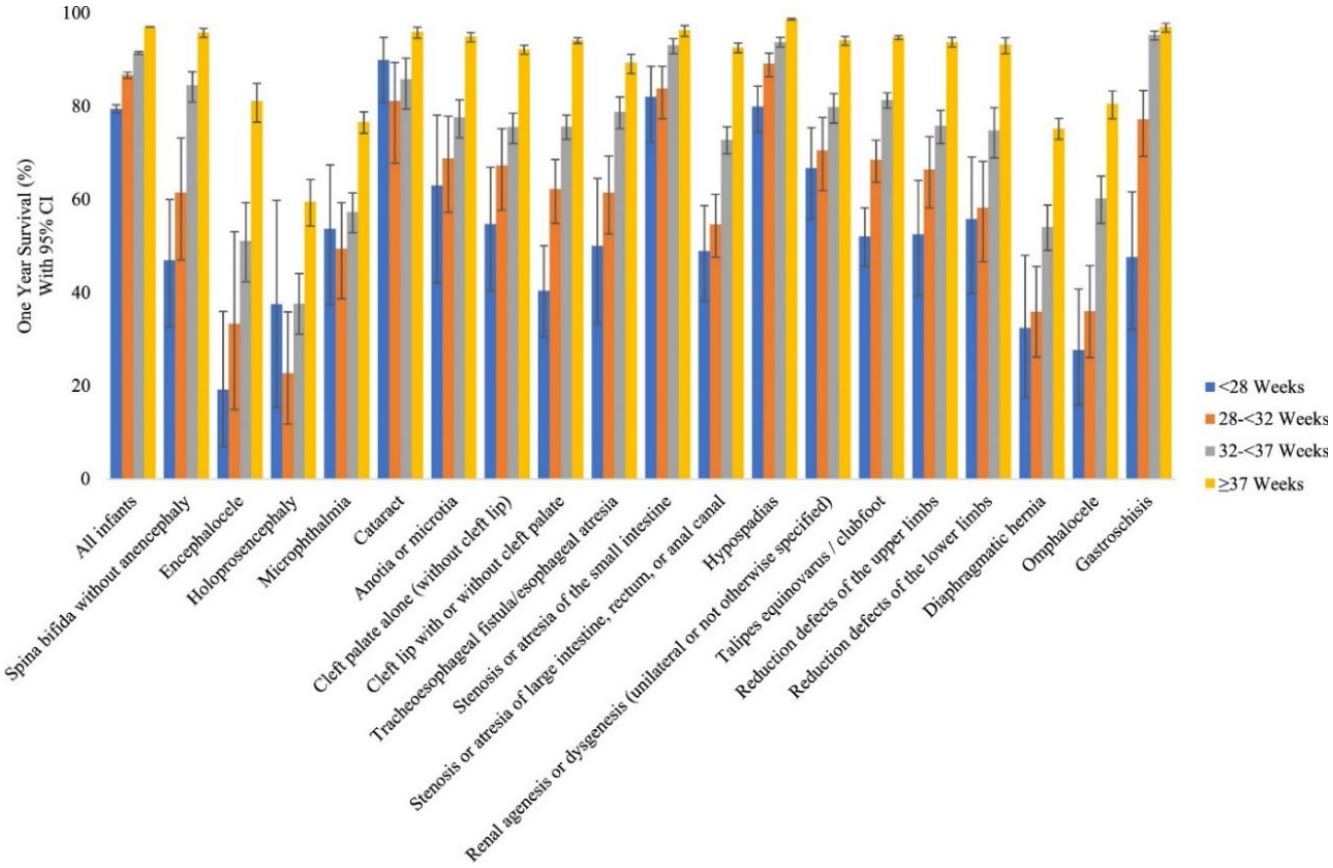
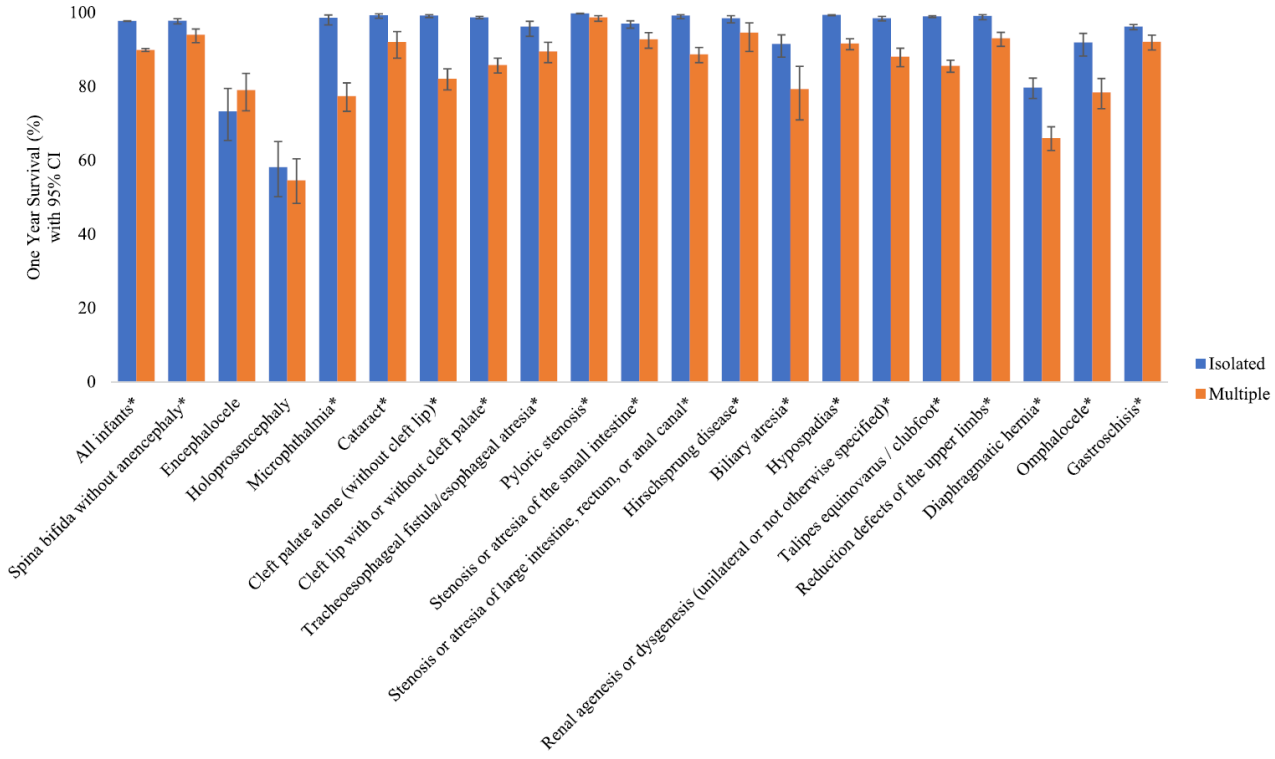


Figure 2: One-year Kaplan–Meier survival estimates in nonsyndromic infants by case classification group, Texas Birth Defects Registry, 1999–2017 births. (*Indicates a significant difference in survival for infants with isolated vs. multiple defects based on chi-square test p<0.05.)



Access to Clinical Genetics Counseling Among Children from the Texas Birth Defects Registry

Many birth defects are caused by more than one risk factor. For example, birth defects may be caused by environmental, behavioral, or genetic factors. Genetic testing and counseling may help a family learn more about the genetic causes of their child's birth defect. Genetic counseling can also help families understand their future risk of having another pregnancy affected by a birth defect.

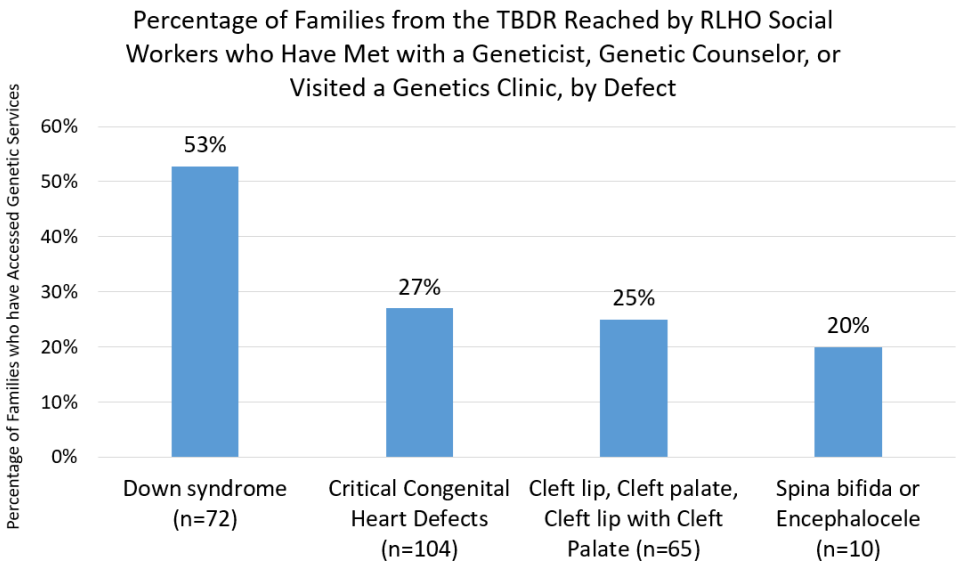
Understanding the genetic causes of a birth defect may help families find better treatments for their child. However, some families may experience barriers to accessing genetic services. For example, some families may not have health insurance to cover the cost of genetic services.

The Birth Defects Epidemiology and Surveillance Branch (BDESB) refers young children with select birth defects (spina bifida, encephalocele, cleft lip/palate, Down syndrome, and or critical congenital heart defects (CCHDs)) from the Texas Birth Defects Registry (TBDR) to DSHS social workers from Regional and Local Health Operations (RLHO). Social workers help families get connected to health and social service programs for medical or financial assistance.

Recently, social workers began asking parents they reached from the TBDR, if they or their child had ever met with a geneticist, genetic counselor, or visited a genetics clinic. If families had *not* met with a geneticist, social workers suggested they ask their doctor about genetic services. Since November 2022, social workers have reached a total of 251 families. Of these 251 families, 83 (33%) reported that they or their child had visited a geneticist, genetics counselor, or genetics clinic. Among the 83 families that had accessed genetics services:

- 70% (58/83) were on Medicaid,
- 28% (23/83) resided in public health service region 6/5S (Houston area), and
- 66% (55/83) reported their child was not meeting CDC developmental milestones

Social workers also referred families to various health and social services programs. Among the 251 families reached, social workers made over 760 referrals to programs.



Thank you to the Texas Department of State Health Services Regional and Local Health Operations (RLHO) Social Workers for assistance with this initiative.

A New Orientation Program for Birth Defects Epidemiology and Surveillance Branch Surveillance Specialists Is Being Developed

In recent years, medical advances in birth defect care have been made. These medical advances have led to more data and medical procedures in medical records. As the amount of data has increased, learning how to abstract cases for the Texas Birth Defects Registry (TBDR) has also become more challenging for new Birth Defects Epidemiology and Surveillance Branch (BDESB) surveillance specialists (SS).

Typically, new SS receive training for six months before beginning to abstract cases independently. Historically, most of this training for new SS has taken place in the BDESB regional offices. BDESB is trying to standardize the orientation training new surveillance staff receive. BDESB has started developing a new orientation training program.

The goal of this new training program is to introduce new SS to the BDESB program. The training will introduce the program mission and provide an overview of their job duties. This training program will equip new staff with basic skills needed to be successful as a SS.

The training modules will introduce:

- the history of the BDESB program,
- technology and software used by surveillance specialists,
- the process of abstracting cases for the TBDR, and
- soft skills/communication best practices needed for their role.

In August 2023, quality assurance specialists met in Austin, TX to develop an outline for this orientation program. In September 2023, DSHS Intern, Praisy Johnson began working with Ada Cavazos, Quality Assurance and Training Coordinator, to develop this training program. BDESB will continue this branch-wide effort to develop this training in 2024.

Changes to Birth Defect Surveillance at Texas Military Facilities

Starting with delivery year 2022, the Texas Birth Defects Epidemiology and Surveillance Branch (the Branch) announced updates to its surveillance practices at certain military facilities, affecting Public Health Regions 7, 8, and 10. This adjustment aims to streamline processes and address challenges specific to military healthcare settings.

The Branch will no longer include surveillance of births at military facilities, including Carl R. Darnall Army Medical Center, Brooke Army Medical Center, and William Beaumont Army Medical Center. Instead, infants born at these facilities will be included in the Texas Birth Defects Registry (TBDR) only if transferred to a non-military facility where routine surveillance is conducted. While this shift might lead to a potential underestimation of birth defect prevalence in certain regions, the analysis indicates a minimal impact, considering that infants born at military facilities represent around 1% of the total TBDR cases.

Several factors influenced this decision, including:

- The Department of Defense's (DoD) Birth and Infant Health Research (BIHR) program already conducts surveillance on birth defects among infants born to military families
- Challenges such as updating electronic health record (EHR) systems at military facilities and the transient nature of the military maternal population contributed to the decision
- Regional surveillance staff faced difficulties obtaining case-finding discharge lists due to the specifics of the DoD military EHR system, leading to resource-intensive 100% chart reviews

The Branch emphasizes that despite these changes, data quality remains a priority. The decision is informed by the recognition that reliance on the DoD BIHR program for military family surveillance, coupled with challenges in obtaining discharge lists, requires a strategic approach to maintain effective birth defect surveillance.

This update reflects the Branch's commitment to adapting surveillance practices to address unique challenges in military healthcare settings. While changes may impact prevalence estimates in specific regions, the decision ensures a balance between resource efficiency and maintaining data quality in the TBDR.

January is National Birth Defects Awareness Month

This is a time to raise awareness about birth defects and highlight efforts to improve the health of people living with these conditions across their lifespan. Join the nationwide effort to raise awareness of birth defects and their impact on individuals, parents, and families. For more information on National Birth Defects Awareness Month, visit cdc.gov/ncbddd/birthdefects/awareness-month.

- There are steps women can take to reduce the risk of birth defects before and during pregnancy. Taking at least 400 micrograms of folic acid every day, preventing infections, visiting the doctor regularly, avoiding harmful substances such as alcohol and tobacco, and managing conditions such as obesity and diabetes, are all some ways that help reduce birth defect risk.
- Birth defects are a leading cause of death among infants in the United States. Improvements in care and screening are important during infancy. Newborn screening for congenital heart defects, for example, is an important tool to identify and provide treatment quickly.
- Some research shows that children born with certain birth defects have difficulty with learning or keeping up with developmental milestones. Access to resources such as Early Childhood Intervention and services such as physical therapy and special education can positively impact the development of a child born with birth defects.
- In adolescence, individuals with certain conditions face new challenges while transitioning from childhood to adulthood, such as changes in insurance and doctors. Some may begin making their own healthcare decisions. Recognizing and planning for these changes can improve the transition to adult health care.
- Birth defects affect individuals in adulthood in many ways. People living with birth defects should talk with their doctor about how pregnancy may affect them and their baby. Women who have had a previous pregnancy affected by a neural tube defect (NTD) are at increased risk for a subsequent NTD-affected pregnancy. To learn about genetic risks of having a baby with a birth defect, individuals can talk with a genetics counselor or clinical geneticist.

Content Source: Centers for Disease Control and Prevention

Mark your calendar – March 3 is World Birth Defects Day.

Recent Publications from the Texas Birth Defects Epidemiology and Surveillance Branch (BDESB) Staff and Collaborators

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2024 Calendar

January
National Birth Defects Prevention Month

February
American Heart Month

International Prenatal Infection Prevention Month

February 7-14
Congenital Heart Defect Awareness Week

Spring 2024
March of Dimes March for Babies (check with MOD for specific dates and locations)

March
National Nutrition Month

National Developmental Disabilities Awareness Month

March 3
World Birth Defects Day

April
Alcohol Awareness Month

National Autism Awareness Month

National Minority Health Month

STD Awareness Month

April 1-7
National Public Health Week

June
National Congenital Cytomegalovirus Awareness Month

June 17-18
37th Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research, Austin, Texas

June 22-26
64th Annual Meeting for the Society for Birth Defects Research and Prevention, Pittsburgh, Pennsylvania

July
National Cleft and Craniofacial Awareness & Prevention Month

July 30
Gastroschisis Awareness Day

September
Newborn Screening Awareness Month

National Infant Mortality Awareness Month

September 8-14
Folic Acid Awareness Week

October
National Spina Bifida Awareness Month

National Down Syndrome Awareness Month

November
Prematurity Awareness Month (March of Dimes)

About The Monitor

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Please visit the BDESB website for updated information and to sign up for Branch updates: www.dshs.texas.gov/birthdefects/.

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