

# Texas Birth Defects Registry

**Our Mission:** To identify and describe the patterns and outcomes of children with birth defects in Texas, and to collaborate with others in research, prevention, and referral to services.

## About the Registry

The Texas Birth Defects Registry was established in 1993 by the Texas Birth Defects Act (Chapter 87 of the Texas Health and Safety Code, Birth Defects) and has been in operation since 1994. Statewide data became available in 1999. Here are a few more facts about the registry:

- Highly-trained regional staff review hospital logs, hospital discharge lists, and other records to find babies with birth defects (structural malformations or chromosomal disorders).
- If the record indicates that the infant or fetus has a birth defect covered by the Registry, demographic and diagnostic information are abstracted from the medical record.
- Over 25,000 cases are entered into the registry each year.
- All information is held in strict confidence in accordance with state and federal privacy laws.
- Quality assurance activities are conducted throughout data collection and processing to monitor the accuracy, completeness, and timeliness of the Registry's data.
- The program's operations are funded by the State of Texas and Federal Block Grant Funds from Title V.

## Data Uses

Data from the Registry provides for:

- ✓ Cluster investigations
- ✓ Studies of mortality and survival
- ✓ Understanding changes over time
- ✓ Prevention and family outreach services
- ✓ Studies of the causes, occurrence, and patterns of birth defects



## Contact Information

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## Birth Defects in Texas

- In recent years, about 6% of all Texas babies were born with one or more birth defects or a chromosomal abnormality.
- One in 63 babies is born with a heart defect.
- One in 930 babies is born with cleft lip.
- One in 743 babies is born with Down syndrome.
- One in 1397 babies is affected by neural tube defects (anencephaly, spina bifida, or encephalocele).
- Certain birth defects exhibit higher rates in some racial/ethnic groups than other groups.



## Birth Defects Mortality

Birth defects are also the leading cause of death among infants in Texas. From 2010 to 2017, they accounted for approximately 26% of all infant deaths before one year of age. Birth defects continue to be one of the top ten causes of death for all age groups through age 29.

## Birth Defects Costs

In 2010, birth defects resulted in nearly 42,000 hospitalizations among children in Texas, with total charges over \$2.2 billion, based on hospital discharge data. Nine of the 10 costliest conditions were heart defects. The average hospitalization visit was 6.2 days and the average charges were \$53,000 per hospitalization. While the average charge per hospitalization is comparable to national data, due to the large population of Texas relative to other states, total charges for hospitalizations of children with birth defects are high.

## Research

Texas Birth Defects Registry data contribute significantly to clinical, epidemiologic, and health services research and investigations. Over 300 peer-reviewed journal articles and reports have been published by Texas Birth Defects Epidemiology and Surveillance Branch and its collaborators, most of which were published using Texas Birth Defects Registry data.

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