

► **OUR MISSION:** TO IDENTIFY AND DESCRIBE THE PATTERNS OF BIRTH DEFECTS IN TEXAS, AND TO COLLABORATE WITH OTHERS IN RESEARCH, PREVENTION, AND REFERRAL TO SERVICES.

# Texas Birth Defects Registry

## 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 visits medical facilities regularly where they have the authority to review 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, detailed demographic and diagnostic information are abstracted and entered into the computer for processing.
- ✓ In recent years, over 20,000 cases per year were entered into the registry.
- ✓ All information is held in strict confidence in accordance with state and federal privacy laws.
- ✓ Quality control procedures help ensure completeness and accuracy.
- ✓ The program is funded by the State of Texas and Federal Block Grant Funds from Title V.



## Quality Assurance

Quality assurance activities are conducted throughout data collection and data processing to monitor the accuracy, completeness, and timeliness of the Registry's data.

## Timeliness

The Texas Birth Defects Registry meets the timeliness standard set by the National Birth Defects Prevention Network (NBDPN) which states that the data for a given delivery year should be at least 95% complete within 24 months following the end of that delivery year.

## Data Uses

Data from the registry are used for many different reasons, although all information is held in strict confidence in accordance with state and federal privacy laws. Data provides for:

- ✓ Cluster investigations
- ✓ Occurrence and patterns of birth defects
- ✓ Prevention and family outreach
- ✓ Studies of access/proximity to services
- ✓ Studies of mortality and survival
- ✓ Studies of causes of birth defects
- ✓ Understanding changes over time

# Texas Birth Defects Registry

## Birth Defects in Texas

- ✓ In recent years, almost 5% of all Texas babies were born with one or more birth defects or a chromosomal abnormality. Boys are roughly one-third more likely to be affected.
- ✓ One in 70 babies in Texas is born with some form of heart defect.
- ✓ One in 927 babies is born with cleft lip.
- ✓ One in 760 babies is born with Down syndrome.
- ✓ One in 1425 babies is affected by neural tube defects (anencephaly, spina bifida, or encephalocele).
- ✓ Approximately 30% of babies with birth defects have more than one major birth defect.
- ✓ Certain birth defects exhibit higher rates in some racial/ethnic groups than other groups.



## Birth Defects Mortality

Birth defects are the leading cause of death among infants in Texas. From 1999-2008, 4.6% of live born babies with a birth defect died before their first birthday. In 2009, birth defects accounted for 22% of all infant deaths. 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 are 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.

## The Research Center

In 1996, the Texas Center for Birth Defects Research and Prevention was established as a part of the Birth Defects Epidemiology and Surveillance Branch of the Texas Department of State Health Services in Austin. The mission of the Texas Center is to conduct research studies to understand the causes of specific birth defects, including participation in the National Birth Defects Prevention Study and other studies.

## Contact Us

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