Birth Defects

About

Birth defects are conditions that are present at birth. They cause structural changes in one or more parts of the body, and may have serious adverse effects on health, development, or functional ability. Today, researchers have identified thousands of different birth defects; some are fatal. In Louisiana, birth defects – along with prematurity - are a leading cause of death in infants (infant mortality). According to the Centers for Disease Control and Prevention (CDC), about 3% of babies in the United States- 1 out of every 33 - is born with a structural birth defect. Meaning that of the approximate 62,000 babies born each year in Louisiana, at least 1,800 are born with a birth defect.

For some birth defects, such as fetal alcohol syndrome, the cause is known, but for most birth defects, the exact cause remains unknown. Currently most birth defects are understood to result from family traits (genetic), parent health and behavior, and/or our environment. It is not well understood how birth defects may be related to exposure to environmental hazards, such as chemicals, air pollution, and radiation, and these remain under study. New research explores the possible connection between exposure to specific environmental hazards and potential increases in the risk of certain birth defects. Birth defects surveillance efforts are expanding. Data compilation, data sharing and transparency, and data query and visualization tools are also improving. The CDC Tracking and Louisiana Department of Health (LDH) Tracking Health Data Portals have been built to assist health officials, analysts and researchers to apply the available data to better understand the relationship between birth defects and the environment.

About the Measures

Measures of birth defects prevalence were developed following the CDC Standards for Nationally Consistent Data and Measures (NCDMs) within the Environmental Public Health Tracking Network. The purpose of NCDMs is to ensure compatibility and comparability of data and measures across and within states, and for the US. They allow for consistency in data use, quality, and interpretation. Applying common data standards makes it possible to find associations and explore trends that may be present in the data, which is useful for better understanding the impact of our environment on our health.
The LDH Health Data Portal contains data on the prevalence of the following birth defects, displayed per 10,000 live births, for 5 year reporting periods, for children up to the age of three years. See 'Additional Info' below for direct links to the CDC website with more in-depth descriptions and information on these birth defects:

- Anencephaly
    - Anencephaly is a rare type of neural tube defect in which a baby is born without parts of the brain and skull. The neural tube is a narrow channel that folds and closes during the third and fourth weeks of pregnancy to form brain and skull, spinal cord, and back bones. Anencephaly occurs when the upper part of the neural tube that forms the brain and skull does not close all the way. This results in the baby's brain not being fully formed or often not being covered by bone or skin when the baby is born.

- Cleft lip with and without Cleft Palate

    - Cleft lip is an opening in the upper lip that occurs when a baby's lip does not form properly during pregnancy. The opening can be a small slit in the lip or it can be a large opening that goes through the lip into the nose. A cleft lip can be on one or both sides of the lip or in the middle of the lip. Children with cleft lip can also have cleft palate. This happens when the roof of the mouth, or palate, does not join together completely during pregnancy.
- Cleft palate without Cleft Lip
    - A cleft palate is an opening in the roof of the mouth, called the palate. A cleft palate does not join together completely during pregnancy. For some babies, both the front and back parts of the palate are open. For other babies, only part of the palate is open.
- Down Syndrome (Trisomy 21)
    - Down syndrome, also known medically as Trisomy 21, is a condition in which a baby is born with an extra chromosome. Chromosomes are small, threadlike structures found in the nucleus of cells that carry genetic information in the form of genes. Normally, a baby is born with 23 pairs (46 total) chromosomes. Babies born with Down syndrome have an extra copy of chromosome 21. This extra copy or piece changes how the baby's body and brain develop, which causes mental and physical challenges. No one knows for sure why Down syndrome occurs, but one factor that increases the risk for having a baby with Down syndrome is the mother's age. Women who are 35 years or older when they become pregnant are more likely to have a pregnancy affected by Down syndrome.
- Gastroschisis
    - Gastroschisis is a birth defect of the abdominal wall that causes a portion of the intestine to protrude outside of the baby's body through an opening beside the belly button. The opening can be small or large. Sometimes other organs, such as the stomach and liver, also protrude outside of the baby's body. Gastroschisis occurs early during pregnancy when the muscles that make up the baby's abdominal wall do not form correctly.
- Hypoplastic Left Heart Syndrome
    - Hypoplastic left heart syndrome is a type of congenital heart defect that affects normal blood flow through the heart. It occurs when the left side of the baby's heart does not form correctly.
- Hypospadias
    - Hypospadias is a birth defect in boys where the opening of the urethra is not located at the tip of the penis. In boys with hypospadias, the urethra forms abnormally during weeks 8-14 of pregnancy. The abnormal opening can form anywhere from just below the end of the penis to the scrotum.
- Upper and Lower Limb Deficiencies
    - Upper limb deficiencies occur when a part of, or the entire, arm of a fetus fails to form completely during pregnancy. Lower limb deficiencies occur when a part of, or the entire leg, of a fetus fails to form completely during pregnancy. These defects are also referred to as "limb reduction" because a limb is reduced from its normal size or is missing.

- Spina Bifida (without Anencephaly)
    - Spina bifida is a neural tube defect that can happen anywhere along the spine when the neural tube does not close all the way. It may be, but is not always apparent at birth. In Spina Bifida without Anencephaly, the backbone that protects the spinal cord does not form and close as it should, which results in damage to the spinal cord and nerves.
- Tetralogy of Fallot
    - Tetralogy of Fallot is a type of congenital heart defect affecting normal blood flow through the heart that occurs when a baby's heart does not form correctly. Tetralogy of Fallot is a combination of as many as four defects: a hole in the wall between the two lower chambers of the heart; a narrowing of the pulmonary valve and main pulmonary artery; an enlarged aorta valve that opens from both ventricles; or the muscular wall of the lower right chamber of the heart is thicker than normal.
- Transposition of the Great Arteries (vessels)
    - Transposition of the Great Arteries is a congenital heart defect that occurs when the two main arteries that carry blood out of the heart - the aorta and the pulmonary artery - are switched in position.

About the Data

- Measures were reported for parishes when there was data available for the 5 year time periods (2005-2009, 2006-2010, and 2007-2011). "No data" was reported when data was not available for the 5 year time periods.
- Live births in the participating hospitals were used to estimate the prevalence of birth defects, which were expressed as cases of defects per 10,000 live births. The prevalence of birth defects is calculated using the following formula: [the number of cases from the same area and time period / the number of live births from the same area and time period] X 10,000.
- 95% confidence intervals were calculated from the Poisson distribution using the formula: %CIPOISS (.95, cases, Lower confidence limit 95, Upper confidence limit 95), Lower Confidence Limit = [Lower confidence limit 95 / live births] X 10,000. Upper confidence limit = [Upper confidence limit 95 / live births] X 10,000. The upper and lower confidence limits used the exact binomial and Poisson confidence limits using Statistical Analysis System (SAS) macro (Daly, 1992).
- The prevalence of birth defects with a relative standard error greater than 30% indicates that data do not meet standards of reliability or precision. Generally, the prevalence of birth defects based on fewer than approximately 12 cases have a relative standard error (RSE) over 30%.
- The birth defect data on the Louisiana Department of Health (LDH) Health Data Portal comes from the LDH Louisiana Birth Defects Monitoring Network (LBDMN). LBDMN conducts active surveillance, of live births only, from approximately 50 birthing hospitals (as of 2017) in Louisiana of children born with congenital medical conditions, from birth up to three years of age.

- Hospital discharge records including selected birth defects are sent to LBDMN staff. All records are reviewed confidentially and sent to the Data Collection Specialist to determine if the patient

met the birth defects' case definition developed by the LBDMN. Some cases of birth defects are not collected, if not diagnosed prior to the third birthday, cases of birth defects following spontaneous abortions, cases of terminations, or fetal losses.

- One child may have multiple birth defects, and therefore more than one diagnosis of different of birth defects. These data do not represent the total number of children with birth defects in Louisiana.
- These data may not include children with birth defects who were not delivered at participating hospitals, who were diagnosed at hospitals where data collection has not occurred or who did not have an inpatient hospital stay.
- Locations are based on the mother's residence at the time of child's birth.
- Out of state births were not included in these data; Mothers who delivered at a Louisiana facility but had out of state residence; or children who sought treatment and were diagnosed in a Louisiana facility but were out of state residents were not included. So no LA birth certificate = not included.
- Measures were not reported for Louisiana administrative regions or parishes (counties) where several parishes within a region did not report incidents of birth defects, or where parishes had either no surveillance or less than an 80% reporting rate.
- For 2005 and 2006, data was included for 26 parishes. For 2007, data was included for 36 parishes. Since some parish data were not available during the 5 year intervals for which birth defects prevalence measures were calculated, these annual measures cannot be used to estimate the number of children with birth defects for the entire state.
- Statewide birth defects data became available for the state beginning in 2008. For 2008, data was included for 64 parishes. However, data collection has not been consistent; for example in LDH Administration Health Regions 4 & 5 for several years. Therefore, the loss of data will be reflected over time and should not be interpreted as a reduction in birth defects. For 2009 data was included for 55 parishes. For 2010, data was included for 39 parishes. For 2011, data was included for 33 parishes.
- Data limitations may prevent some comparisons of these data to those from other states. Not all states in the United States have a birth defects surveillance program. Among those that do, there is significant variability between surveillance systems. States that have programs may have different methods for collecting and coding data, identifying and verifying cases.
- Birth defects are coded based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) and the British Pediatric Association Classification of Diseases (BPA):
- Anencephaly is classified as any primary or other diagnosis codes of 740.00-740.10 are included in the calculation of measures.
- Cleft lip with Cleft Palate is classified as any primary or other diagnosis codes of 749.20-749.29 are included in the calculation of measures.
- Cleft lip without Cleft Palate is classified as any primary or other diagnosis codes of 749.10-749.19 are included in the calculation of measures.

- Cleft palate without Cleft lip is classified as any primary or other diagnosis codes of 749.00-749.09 are included in the calculation of measures.

- Down syndrome is classified as any primary or other diagnosis codes of 758.00-758.09 are included in the calculation of measures.
- Gastroschisis is classified as any primary or other diagnosis codes of 756.71 are included in the calculation of measures.
- Hypoplastic Left Heart syndrome is classified as any primary or other diagnosis codes of 746.71 are included in the calculation of measures.
- Hypospadias is classified as any primary or other diagnosis codes of 752.60-752.62 (excluding 752.61 and 752.621) are included in the calculation of measures.
- Limb Deficiencies combined is classified as any primary or other diagnosis codes of 755.20-755.49 are included in the calculation of measures.
- Spina Bifida (without anencephaly) is classified as any primary or other diagnosis codes of 741.00-741.99 without 740.00-740.10 are included in the calculation of measures.
- Tetralogy of Fallot is classified as any primary or other diagnosis codes of 745.20-745.21, 747.31 are included in the calculation of measures.
- Transposition of the Great Arteries is classified as any primary or other diagnosis codes of 745.10-745.12, 745.18-745.19 (note: for CCHD, 745.10 (TGA complete, no VSD), 745.11 (TGA incomplete, with VSD), 745.18 (other specified TGA), 745.19 (unspecified TGA)) are included in the calculation of measures.

Disclaimer

Data are intended to spur further research and should be used only as a starting point to understanding how the environment and other contributing factors may be connected to disease. Datasets presented on this site are intended to answer some basic questions, but should ultimately lead to further inquiry and more detailed study.

Data limitations should be noted if conducting exploratory ecological studies with these data. Limitations may include data gaps, reporting discrepancies (for example, a disruption of reporting or instrument recording following hurricanes) and insufficient data on all potentially confounding factors. There are numerous additional factors which may contribute to disease onset. These include genetics, access to health care, existing health conditions, medicines, other chemical substances we come into contact with or ingest, nutrition, route and duration of exposure, level of activity, level of stress, and many others.

Responsible use of this data therefore requires exercising caution when drawing conclusions based solely on views of the limited available data. Any perceived relationship, trend, or pattern apparent in the data should not be interpreted to imply causation; may in fact be unrelated; and should be regarded as preliminary, and potentially erroneous, until more in-depth study and if applicable, statistical evaluation, can be applied. The LDH Bureau of Health Informatics and Environmental Public Health Tracking Program cannot guarantee the completeness of the information contained in these datasets and expressly disclaim liability for errors and omissions in their content.

Data Sources

- LDH Louisiana Birth Defects Monitoring Network

Additional Information

- CDC Birth Defects Info

Questions

- Email: healthdata@la.gov