

Michigan Birth Defects Metadata

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Abstract

The Michigan Department of Health and Human Services (MDHHS) Michigan Environmental Public Health Tracking Program (MiTracking) worked with the Michigan Birth Defects Registry (MBDR) to create a dataset that includes information on twelve birth defects. Birth defects are physical or developmental conditions that affect about 1 in 33 babies born in the U.S. each year, and thousands of Michigan children. Most birth defects originate in the first three months of pregnancy when the tissues and organs of the baby are forming, but some occur later in pregnancy. Some birth defects can be life threatening.

The data include the following indicators:

1. Anencephaly.
2. Cleft Lip with Cleft Palate.
3. Cleft Lip without Cleft Palate.
4. Cleft Palate without Cleft Lip.
5. Gastroschisis.
6. Hypoplastic Left Heart Syndrome.
7. Hypospadias.
8. Limb Deficiencies (upper and lower).
9. Spina Bifida (without Anencephaly).
10. Tetralogy of Fallot.
11. Transposition of the Great Arteries (vessels).
12. Trisomy 21 (Down Syndrome).

This dataset is updated every year.

MiTracking obtained these data through a Data Sharing Agreement and a Scientific Advisory Review Board review. MiTracking calculated rates using Michigan resident live birth and birth defect data from the Division of Vital Records and Health Statistics (DVRHS). The birth defect data includes birth defects of Michigan residents diagnosed in Michigan. The live birth dataset contains all births to Michigan residents, including births taking place in another state.

All users are recommended to read and fully comprehend the metadata prior to data use. To access these data, [please visit the MiTracking Data Portal](#).

Purpose

The Centers for Disease Control and Prevention National Environmental Public Health Tracking Program (CDC Tracking) and MiTracking use this dataset to calculate the Nationally Consistent Data and Measures (NCDMs). NCDMs are for one-year and five-year incidence counts and rates for birth defects. CDC Tracking and MiTracking provide public health professionals, researchers, MiTracking grantees and the public with Michigan birth defects aggregate information.

Supplemental Information

The MBDR maintains reports from birth to two years of age to Michigan residents who are diagnosed with a reportable condition. Hospitals, clinical and pathology laboratories report this information to the MBDR as mandated by Public Act 236 of 1988 which amended the Public Health Code, Act 368 of 1978. Public Act 236 directed the MDHHS to establish a comprehensive birth defects registry. The MBDR provides the information needed to:

- Compute baseline birth defects incidence and mortality rates and analyze trends.
- Identify and respond to potential clusters.
- Formulate and test hypotheses.
- Plan and develop relevant programs.
- Coordinate assistance for long-term care and follow up.
- Evaluate programs and services.
- Further educate professionals and the community at large.

These activities help to increase birth defects prevention knowledge and to assure that Michigan children with birth defects have access to available resources and assistance. The statewide registry's successful functioning and the data quality is important in meeting these goals.

The MBDR collects data on Michigan resident birth defects that are diagnosed and/or treated in Michigan. These data are considered complete as of their publication date. Suppression occurs in small numbers and unreliable rates have been suppressed. Data have been de-identified to protect patient confidentiality.

Data limitations:

- Birth defects cases or rates may change over time for many reasons. For example, a

new and better technique may detect a specific birth defect. Because of this technique, more cases will be detected. This would not mean that there are more cases of birth defects.

- Changes over time could also be due to changes in reporting methods.
- The MDBR recently updated its case reporting system. These changes, which increase case reporting and include a new protocol for data quality checks, is retroactive to January 1, 2018. Thus, data collected from 2018 to the present may differ from previous reports. Increases in some birth defects between 2000-2017 and 2018-current may in part be due to the improved data reporting process and not necessarily an increase in hospitalizations or birth defect diagnoses. Additionally, facilities now have a strict reporting schedule for birth defect cases and all cases are submitted electronically. This allows for more complete data and streamlines compliance checks.
- Cases or rates may change over time or be different for geographic areas for many reasons. Genetics, behaviors, and other personal characteristics such as access to medical care and diet can impact the likelihood of having a baby with a birth defect.
- The MBDR does not obtain information on cases diagnosed or treated out of state. This would cause some undercount of the actual numbers (and the corresponding rates) of Michigan resident birth defect cases. An undercount for this particular reason may be more likely to occur among people living in counties bordering neighboring states since this group could be more likely to seek treatment at an out of state facility. The extent of the undercount is unknown.
- There are many things that may help to cause birth defects. The data on the Data Portal cannot tell us the cause of any birth defect.

Keywords

Anencephaly; Q00.0, Craniorachischisis; Q00.1, Spina Bifida; Q05, Cervical spina bifida without hydrocephalus; Q05.5, Lumbar spina bifida without hydrocephalus; Q05.7, Sacral spina bifida without hydrocephalus; Q05.8, Hypoplastic left heart syndrome; Q23.4, Tetralogy of fallot; Q21.3, Discordant ventriculoarterial connection; Q20.3, Discordant atrioventricular connection; Q20.5, Cleft palate with cleft lip; Q37, Cleft lip; Q36, Cleft palate; Q35, Reduction defects of upper limb; Q71, Reduction defects of lower limb; Q72, Reduction defects of unspecified limb; Q73, Down's syndrome; Q90, Hypospadias; Q54, Gastroschisis; Q79.3, Health outcomes; health effects; birth defects; adverse reproductive outcomes; neural tube defects; NTD; Cardiac anomalies; heart defects; congenital heart defect; congenital heart disease; CHD; Oral clefts; Orofacial cleft; genital disorder; reproductive disorder; Gastroschisis; Gastroschisis (disorder).

Bounding Coordinates

Geographically, all cases in this dataset occurred for Michigan residents. This means that all cases were for Michigan residents within the latitude/longitude coordinates listed below:

- West Bounding Coordinate: -90.418133999999995.
- East Bounding Coordinate: -82.418394000000006.
- North Bounding Coordinate: 48.189534000000002.
- South Bounding Coordinate: 41.696088000000003.

Other Information on Data

- **Level of Geographic Detail:** Statewide and County.
- **Currentness Reference (when data were last updated):** 4/1/2024.
- **Frequency at which the data are updated:** Annually.
- **Data Status:** Complete.

Completeness Report

Changes in the number of birth defects may reflect a birth defect reporting or identification change, rather than a change in the actual number of cases. It is essential to consider the following three factors when comparing frequencies over time or between geographic areas.

- **Inconsistent or Incomplete Reporting** – Implementation of the new reporting system has revealed evidence that some facilities were not submitting all reportable cases. Thus, there could be significant shifts in the number of reported cases in counties where such problems existed.
- **Over Reporting** – Sometimes a birth defects case is reported to the registry, but the diagnosis is later ruled out. If the original report is not corrected, the result is over reporting.
- **Resident Interstate Information Exchange is Lacking** – The MBDR does not obtain information on children diagnosed or treated for a birth defect in a facility outside of Michigan. This would cause an undercount of the actual case numbers (and the corresponding rates). Counties that border neighboring states could have more of an undercount for this reason than other counties.

Data Processing Description

Data Source: MiTracking staff requested birth defect and total live birth counts data files from the DVRHS through the MBDR and Birth Certificate files following a signed Data Sharing Agreement and review from the Scientific Advisory Board. MBDR processed and created the dataset.

Inclusion Criteria: The dataset was prepared following the CDC How-to-Guide for Birth Defects, May 2022 instructions.

Data Calculations:

Average Annual Number of Cases among Live Births over a Five-Year Period: All new cases of each birth defect for live births to women living in Michigan and each Michigan county were

averaged over five-year periods. This step was repeated for each available five-year range of data.

To protect individuals, many years of data were grouped together because the number of cases per year was too small to provide to the public. Data for five-year periods were divided by five years to obtain an average annual number of cases. An average annual number of birth defects is a good estimate of how many infants were born with a specific birth defect per year in the five-year range but may not be the exact number recorded for each year.

Rate per 10,000 Live Births over a Five-Year Period: All new cases of each birth defect for live births to women living in Michigan and each Michigan county were averaged over a five-year period. That number was divided by the average number of live births in Michigan (and each county) over that five-year period. Because birth defects are rare, the result was multiplied by 10,000 to get the number of new cases for every 10,000 live births. These steps were repeated for each available five-year range of data.

Suppression: MiTracking has applied appropriate cell suppression rules imposed by the data providers and/or using CDC guidance. Even at the county level it can be expected that the measures generated will often be based upon numbers too small to report or present without violating state and federal privacy guidelines and regulations. Staff have adhered to the cell suppression rules by suppressing all counts greater than 0 and less than 6, along with their corresponding rates, over a 5-year period. We display annual average number of birth defects on the Data Portal. For example, if there are 6 cases over 5 years, the average annual count will be rounded and displayed (in this case, “1” would be displayed). Complimentary suppression has also been completed to prevent any back calculation of suppressed cells.

Access Constraints

There are no access constraints for data available through the MiTracking Data Portal. Where applicable, restricted data will only be released to users after a written request detailing the purpose of the request, intended use for the data and specifics on the security and privacy measures to be taken to safeguard patient privacy and prevent unauthorized data access or use.

Although these data are intended for use on the CDC National Tracking Network Portal and the MiTracking Portal, there may be certain requirements related to privacy/disclosure concerns, given the potentially sensitive nature of the data. Such requirements may involve suppression when there are small counts. Data will be displayed via the national and Michigan Portals only when sufficient conditions have been met to protect data privacy.

To protect individuals and the statistical reliability of these data, counts greater than 0 and less than 6 for any given geographical region over a 5-year period, along with its corresponding rate, have been suppressed. Additionally, complimentary suppression has been done to prevent back-calculation of any suppressed count.

Use Constraints

All users are recommended to read and fully comprehend the metadata prior to data use. Efforts have been made to ensure the accuracy of the data. These data are supplied by the MBDR for the MiTracking program for the purposes of compiling, integrating and disseminating health effects data. MDHHS specifically disclaims responsibility for any analyses, interpretations or conclusions made by those who access this information.

These data remain the property of the MBDR. They cannot be used for commercial purposes and shall not be used to engage in any method, act or practice which constitutes the solicitation or advertisement of goods, services or real estate to Michigan consumers.

Data users are prohibited from attempting to learn the identity of any person included in the data and from linking these data with any other data for the purpose of matching records to identify individuals or entities (such as hospitals).

Differences in rates over time or by area may reflect differences or changes in diagnostic techniques and criteria, in the birth defects coding, or in changes to case reporting.

Rate differences by area may be due to different socio-demographic characteristics and associated behaviors. When comparing rates across geographic areas, a variety of non-environmental factors, such as access to medical care and diet, can impact the likelihood of infants born with a birth defect.

Security Handling Description

If data are distributed, the use constraints specified in this metadata apply to all recipients of the data.

Confidentiality of all data is required by law and strictly maintained by MDHHS staff. Section 2631 of the Public Health Code regulates procedures protecting confidentiality and regulating disclosure of data and records.

Distribution Liability

The MiTracking Environmental Public Health Tracking Program is maintained, managed and operated by the Environmental Health Bureau (EHB) within MDHHS. In preparation of these data, every effort has been made to offer the most current, correct, complete and clearly expressed information possible. Nevertheless, some errors in the data may exist. In particular, MDHHS disclaims any responsibility for source data, compilation and typographical errors and accuracy of the information that may be contained in these data.

These data do not represent the official legal version of source documents or data used to compile these data. MDHHS further reserves the right to make changes to these data at any time without notice.

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If errors or otherwise inappropriate information is brought to our attention, a reasonable effort will be made to fix or remove it. Such concerns should be addressed to the MiTracking Program.

Custom Order Process

For access to national and multi-state unrestricted or public use data, [please see: CDC Tracking](#).

For more information or access to unrestricted or public use Michigan-specific data about birth defects, [please visit the Michigan Birth Defects data](#).

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