

MICHIGAN BIRTH DEFECTS

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Abstract

This dataset allows for calculation of single year or five-year counts and rates, by maternal age (groupings), maternal ethnicity/race, infant sex, and maternal county and/or state of residence for ten specific birth defects. These birth defects are:

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

Data from the Michigan Birth Defects Registry (MBDR) were used to create this dataset through the Michigan Department of Health and Human Services (MDHHS), Division of Vital Records and Health Statistics (DVRHS). The Michigan Tracking (MiTracking) Program obtained these data through a Data Use Agreement and review by the Scientific Advisory Review Board. The live birth data from Michigan residents, used to calculate rates, were also obtained from the DVRHS. This dataset is resident/occurrent, meaning for births taking place in Michigan to Michigan residents only.

Purpose

This dataset can be used to calculate the nationally consistent data and measures (single year and five-year incidence counts and rates) for birth defects for use on the national and Michigan public portals. The public data portal will provide public health professionals, researchers, Tracking grantees, and the general public with aggregate information on birth defects in the State of Michigan.

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 happen in the first 3 months of pregnancy when the tissues and organs of the baby are forming, but some happen later in pregnancy. Some birth defects can be life threatening.

Supplemental Information

The MBDR maintains a file of reports from birth to two years of age for children born in Michigan or to Michigan residents and who are diagnosed with a reportable condition in the State of Michigan. This information is reported to the MBDR by hospitals, clinical, and pathology laboratories 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; and further educate professionals and the community at large. These activities seek to improve knowledge concerning the prevention of birth defects and to assure that Michigan children with birth defects have access to available resources and assistance. The ability to meet these goals is largely dependent on the successful functioning of a statewide registry and the quality of the data collected.

The resident/occurrent data reduces bias for Michigan counties that border other states and more accurately ties the numerator of live births with a birth defect to the denominator of total live births. These data are considered complete as of their publication date. Data have been de-identified to protect patient confidentiality. Small numbers and unreliable rates have been suppressed.

Limitations of the data:

- Cases or rates of birth defects may change over time for many reasons. For example, a new and better technique may be developed to detect a specific birth defect. Because of this technique, more cases will be detected than by using the old technique, but this would not mean that there are more cases of birth defects.
- Cases or rates of birth defects may change over time because of a change in reporting or identification, rather than a change in trend based in inconsistent or incomplete reporting or over reporting.
- 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.
- Rates are calculated only for resident children who were also born in Michigan and not children diagnosed with or treated for a birth defect in a facility outside of the state, causing an undercount of the actual number of cases, especially for counties that border areas outside of Michigan.
- There are many things that may help to cause birth defects. The data on the 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

West Bounding Coordinate: -90.41813399999995

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): 3/20/2017

Frequency at which the data are updated: Annually

Data Status: Complete

Completeness Report

Changes in the number of birth defects cases may reflect a change in birth defect reporting or identification, rather than a change in trend. In particular, during the late 1990's, certain reporting and diagnostic practices contributed to the number of cases identified. The completeness of the data is affected by three factors that relate to data accuracy and comparability. It is essential that these factors be considered in using the information particularly when comparing frequencies over time or between geographic areas. These factors are:

- (1) Inconsistent or Incomplete Reporting - There is evidence that some of the facilities required to provide these reports are not reporting all cases that should be reported. Very low birth defects frequencies and significant shifts in the number of reported cases can be expected for counties where such problems exist.
- (2) Over Reporting - The ongoing review of reports received has identified that in certain hospitals, a report that a child has a reportable condition will be submitted, but the diagnosis is later ruled out and the original report is not corrected accordingly, resulting in an over count of the number of cases.
- (3) Resident Interstate Information Exchange is lacking - Rates are calculated only for resident children who were also born in Michigan and not children diagnosed with or treated for a birth defect in a facility outside of the state, causing an undercount of the actual number of cases.

Data Processing Description

The dataset was processed and created using data from the MBDR. The dataset was prepared using the instructions found in the Centers for Disease Control and Prevention (CDC) How-to-Guide for Birth Defects, Feb 3, 2016.

MiTracking staff requested birth defect and total live birth counts in data files from the DVRHS through the MBDR and Birth Certificate files following a signed Data Use Agreement and review from the Scientific Advisory Board. Measures were calculated by MiTracking staff through CDC Tracking Program guidance.

The Michigan Environmental Public Health Tracking Program and its data partners have applied appropriate cell suppression rules imposed by the data providers and/or using guidance from the

CDC. 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 and rates greater than 0 and less than 6 over a 5-year period. We display **annual average** number of birth defects on the portal. For example, if there are 6 cases over 5 years, the average annual count will be rounded and displayed. Complimentary suppression has also been completed to prevent any back calculation of suppressed cells. For some data, it was necessary to increase cell sizes by combining data across time (e.g., years) and geographic areas (statewide instead of county-level data).

Access Constraints

There are no access constraints for data available through the Michigan Environmental Public Health Tracking program public portal.

Although these data are intended for use on the Centers for Disease Control and Prevention's National Tracking Network public portal and the Michigan Environmental Public Health Tracking data 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 public portals only when sufficient conditions have been met to protect data privacy.

To protect individuals and the statistical reliability of these data, counts 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

It is recommended that all users read and fully comprehend metadata prior to data use.

These data cannot be used for commercial purposes and shall not be used to engage in any method, act, or practice to conduct 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 and in the coding of birth defects.

Differences in rates 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 the Health Department staff. Section 2631 of the Public Health Code regulates procedures protecting confidentiality and regulating disclosure of data and records.

Distribution Liability

The Michigan Public Health Tracking Network is maintained, managed, and operated by the Division of Environmental Health (DEH) 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 this data at any time without notice.

It is strongly recommended that careful attention be paid to the contents of the metadata file associated with these data to evaluate data set limitations, restrictions, or intended uses. MDHHS shall not be held liable for improper or incorrect use of the data described and/or contained herein.

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MDHHS shall not be liable, without limitations, for any direct, indirect, special, incidental, compensatory, or consequential damages, or third-party claims, resulting from the use or misuse of the acquired data, even if MDHHS has been advised of the possibility of such potential damages or loss. Format compatibility is the user's responsibility.

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Use of the data with other data shall not terminate, void, or otherwise contradict this statement of liability.

The sale or resale of the data, or any portions thereof, is prohibited unless with the express written permission of MDHHS, MBDR, and the DVRHS. These data may not be used for commercial purposes without first obtaining written permission from the MBDR and the DVRHS.

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 Michigan Tracking Program via email or telephone (See Contact Information below).

Custom Order Process

For access to national and multi-state unrestricted or public use data, please see:

<http://ephtracking.cdc.gov>

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

Contact Information

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