

# Monitoring Infants and Children with Special Health Needs

## Birth Defects Prevalence and Mortality in Michigan, 1992-2008



*A report prepared by*

**Michigan Department of Community Health**

*Bureau of Disease Control, Prevention and Epidemiology*



## Surveillance Report

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# Executive Summary

This report presents an overview of the Birth Defects Program at the Michigan Department of Community Health (MDCH). The program aims to monitor trends, promote prevention, and link families to resources. Statewide surveillance data from the Michigan Birth Defects Registry (MBDR) are included for the birth cohort years of 1992 to 2008, along with in-depth analyses of neural tube defects (NTD), orofacial clefts, chromosomal anomalies, and congenital heart defects (CHD).

## **Surveillance**

Michigan's formal surveillance system for monitoring the occurrence of birth defects began in 1988 when the public health code was amended by Act 48 (Public Act 368) to require establishment of a birth defects registry. Case reporting began in 1992 and continues today as a passive system that relies on reporting from hospitals, cytogenetic laboratories and pediatric genetics clinics for case ascertainment.

### **Goals of the Michigan Birth Defects Registry**

- 1)** Maintain, improve and expand Michigan's population-based birth defects surveillance system.
- 2)** Use surveillance data to plan and implement population-based birth defects prevention activities.
- 3)** Use surveillance data to improve access to health services and early intervention programs for children with birth defects and their families.

## **Prevalence**

During 2008, there were 9,054 children with birth defects reported to MBDR within the first year of life, which corresponds to an incidence rate of 746.8 cases per 10,000 resident live births, or approximately 7.5% of the annual birth cohort of 121,231 Michigan newborns. Anomalies of the heart and circulatory system constitute about 25% of the birth defects reported to the MBDR, while anomalies of the musculoskeletal system make up about 17%, and anomalies of the genitourinary system make up about 16% of the birth defects reported to the MBDR.

Analysis of selected MBDR data to determine birth defect prevalence shows an overall rate of: 6.4 cases of neural tube defects; 15.7 cases of orofacial clefts; 11.4 cases of Down syndrome; 1.3 cases of trisomy 18; 1.0 cases of trisomy 13; and 151.7 cases of congenital heart defects all per 10,000 live births from 1992 to 2008. Trends by birth year, maternal age, gestational age, and maternal race and ethnicity are presented in this report.

## **Mortality**

The infant death rate for infants born from 1992 to 2008 with a reportable birth defect was 39.6 deaths per 1,000 infants diagnosed with a birth defect. This compares to an infant death rate of 8.4 deaths per 1,000 live births for all resident infants. The data highlight and reinforce the need to address birth defects as part of public health efforts aimed at reducing infant mortality.

## **Follow-Up**

The follow-up component of the Birth Defects Program helps to link families with available resources and support systems. Follow-up with families of infants with NTDs, in particular, helps to assure they receive available services and that mothers are aware of the increased doses of folic acid needed to reduce the chance of recurrence of Neural Tube Defects (NTD), such as spina bifida, in future pregnancies. A list of available state and national resources for families of children with birth defects is included at the end of this report.

### ***A Closer Look***

The '*Closer Look*' section highlights the Healthy People 2020 objectives related to preconception health. Highlighted indicators include multivitamin/folic acid intake, tobacco and alcohol use during pregnancy, and pre-pregnancy BMI and are assessed for years 2004 to 2008. Michigan has not yet reached the Healthy People 2020 goals for tobacco and alcohol use during pregnancy or pre-pregnancy BMI but has met the multivitamin use goal. Program specific activities related to each indicator are highlighted in the '*Closer Look*' section.

### ***Prevention***

In the realm of birth defects, there are often more questions than answers concerning causality and prevention. However, certain strategies, such as maternal consumption of folic acid before conception and early in pregnancy, or controlling blood sugar levels for mothers with diabetes before and during pregnancy, are known to be effective in reducing the risk of birth defects. The Birth Defects Program supports a variety of outreach activities to help women of reproductive age know the importance of achieving and maintaining optimal health prior to conception in order to optimize babies' health.

### ***A Sound Investment***

The data, analyses and program information outlined in this report represent some of the endeavors undertaken by staff members over the past years. Birth defects surveillance is a sound investment in the current and future health of all Michigan residents. The MDCH Birth Defects Program will continue working to improve health outcomes for Michigan babies by collecting and analyzing data to better understand causes and demographic patterns; by decreasing preventable birth defects; and by linking affected children and their families to services.

# Introduction

This fourth birth defects report is based on data collected by the Michigan Birth Defects Registry (MBDR) from 1992 to 2008. The registry covers more than 1,050 diagnoses reported on children from birth through two years of age. The report serves as a way to share MBDR findings with partners and stakeholders concerned about Michigan infants and children with special health needs. This report focuses on NTD, orofacial clefts, chromosomal anomalies and congenital heart defects with a special section on Healthy People 2020 objectives related to preconception health. Previous reports can be accessed online under “Statistics and Reports” at [www.michigan.gov/mchept](http://www.michigan.gov/mchept).

The Birth Defects Team recognizes the support and direction provided by the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities, which has done so much in advancing the development of Michigan’s birth defects surveillance system.

## Public Health Impact of Birth Defects

Birth defects are a serious public health problem in Michigan and across the nation. During 2008, there were 9,054 children with birth defects reported to the MBDR in the first year of life. This corresponds to a prevalence of 746.8 cases per 10,000 resident live births, or approximately 7.5% of the 121,231 Michigan newborns in 2008.<sup>1</sup> Birth defects contribute significantly to childhood mortality, morbidity, and long-term disability. The infant fatality rate for children born in 2008 with a reportable birth defect was 35.3 deaths per 1,000 infants with a birth defect. This compares to an infant death rate of 7.4 deaths per 1,000 live births for all resident infants born in Michigan for the same year.<sup>2</sup> Recent analysis of MBDR surveillance data reveals that children with birth defects are at much greater risk of death due to causes other than a birth defect (for example, accidental causes).<sup>3</sup> The total mortality rate over ten years of life, for those born in 1997 and reported to the MBDR, was 59.6 deaths per 1,000 children with a birth defect, compared to a rate of 10.5 deaths per 1,000 resident live births overall. This is higher than the 1 in 5 infant deaths usually attributed to birth defects based on death records alone and emphasizes the need for greater attention on the impact of birth defects as a cause of early childhood death.

Children with birth defects often require highly specialized and expensive medical care. Support for the family and affected child may be provided not only by a primary care physician in a medical home and by a variety of medical specialists, but also by adjunct health services, the educational system, community and social organizations, and local or national programs. The ability to use comprehensive data on the incidence and types of birth defects affecting Michigan children will lead to a better understanding of total health care and educational costs for this population; prevention and intervention strategies to reduce both the financial and emotional burden on families and society; and an improvement in the quality of life for affected children and their families.

In 2008, the fatality rate was 35.3 deaths per 1,000 babies *reported with birth defects*, compared to 7.4 deaths per 1,000 live births *for all infants*.



# Michigan's Birth Defects Program

## PREVENTION

Data from the MBDR is used to effectively plan and implement prevention activities. Prevention activities to promote good preconception health have included: multivitamin distribution; raising awareness among teens of the risk of adverse birth outcomes related to having uncontrolled diabetes mellitus; partnering with programs such as Michigan Healthy Mothers, Healthy Babies, March of Dimes, and local public health; and participation in the National Birth Defects Prevention Network (NBDPN), promoting Birth Defects Prevention Month.

In 2008 and 2009, the Birth Defects Program received a March of Dimes Michigan Chapter Community Grant for the project, *Teens with Diabetes Mellitus: Promoting Preconception Care to Prevent Adverse Pregnancy Outcomes*. Surveys assessed female teens' and parents' awareness and concerns with the risks of adverse pregnancy outcomes related to a woman having uncontrolled diabetes prior to and during pregnancy as well as routine activities related to having diabetes (such as receiving diabetes information and frequency of doctor visits). Health care providers were surveyed to assess visits with diabetic patients and information given to patients. Results revealed that only about 45% of teens and 55% of parents who responded were aware of the risks of adverse birth outcomes related to uncontrolled diabetes.



As a result, a fact card targeting teens entitled, *The Birds and the Bees...and Diabetes*, was created in English and Spanish. In addition, a preconception toolkit focused on all women of child bearing age with pregestational diabetes was developed for health professionals to provide information on reproductive risks and birth defects, management guidelines before and during pregnancy, and prevention educational resources.

## MONITORING

Statewide monitoring of birth defects is conducted by the Michigan Birth Defects Registry (MBDR) in the Division of Vital Records and Health Statistics. The confidential registry is a passive system of ascertainment that relies on reports submitted by all Michigan hospitals and cytogenetic laboratories. Initiatives for voluntary case reporting to the MBDR by outpatient pediatric genetic clinics, and others, have contributed additional cases of birth defects that would otherwise have gone undetected. About 10,000 Michigan children are born annually with birth defects or other reportable conditions. The MBDR currently contains about 450,000 reports on more than 150,000 individual children born from 1992 to 2008. Epidemiology and vital records staff analyze registry data and conduct special studies to better understand the impact of birth defects on public health.

## The Michigan Birth Defects Registry (MBDR)

The *purpose* of the MBDR is to:

- Collect statistical data on the incidence of birth defects in Michigan.
- Conduct birth defects surveillance and epidemiologic studies on the causes of birth defects.
- Provide data for birth defect prevention and intervention efforts, program planning and evaluation.
- Assure that children with birth defects and their families receive appropriate support services.

Examples of uses for MBDR data include monitoring the rate and types of birth defects in specific geographic areas, planning and evaluating service delivery to children with special needs, targeting birth defects prevention activities and conducting scientific research on the etiology of birth defects.

## Reportable Conditions

The MBDR currently collects information on children from birth to two years of age who have a reportable condition and were born in Michigan to Michigan residents. Reportable diagnoses include all congenital anomalies of consequence, genetic disorders presenting at birth or in early childhood, and selected maternal exposures to infectious disease and other teratogenic agents such as alcohol. The MBDR includes in the case definitions all those birth defects identified in the NBDPN's Guidelines for Conducting Birth Defects Surveillance—Appendix 3.1, by ICD-9-CM code.

Previously, only live born children were included in the registry, but since June 1, 2003, fetal deaths with any of these conditions are also reportable to the registry. Condition coding is accomplished using the current year version of the Ninth Revision of the International Classification of Diseases: Clinical Modification (ICD-9-CM). A manual that includes a list of reportable ICD-9 codes, enabling legislation and reporting instructions is provided to hospitals, cytogenetic laboratories and other reporting facilities. A list of reportable ICD-9 codes by diagnostic category is included in this report as Appendix B. The MBDR Reporting Manual and Reporting Forms can be found online at [www.michigan.gov/mbdr](http://www.michigan.gov/mbdr).



The rules regulating birth defect reporting have been updated. Revisions include establishing the authority to expand the range for age at diagnosis for selected conditions, redefining what conditions are reportable by using terms rather than diagnostic codes, and expanding the ability of the MBDR to include specialized reporting sources and to designate agencies other than MDCH to act on behalf of the MBDR. These changes are expected to improve the effectiveness of the registry as a monitoring system for conditions such as fetal alcohol syndrome, autism, developmental delay, and others that typically become apparent later in childhood; and to enhance our ability for collaborative outreach efforts.

## Reporting Methods

Since the MBDR relies on data collected through passive case ascertainment, staff members help facilities identify the reporting method best suited to their needs. Methods of reporting cases to the registry include:

- Paper Abstract: This method uses a standardized form in paper abstract for hospital admissions and cytogenetic laboratory results.
- Electronic Submission: This method uses facility discharge data to create an electronic record of children admitted with reportable conditions.
- Electronic Birth Certificate (EBC): This method utilizes Genesis, the software commonly used to create electronic birth records for children born at a facility.

Roughly 85% of all reports are received in electronic form, with about half of those being received through EBC and half as hospital-specific data files. Report processing procedures include de-duplicating

and consolidating case reports, report review and query, coding and editing reported information and linking case information to Michigan birth and death files. Data from all three sources (reports, births and deaths) are used to develop a complete record on each case.

As an important public health indicator, birth defect reporting is mandated by state law and parental consent is not required in order to file a report. However, both law and rule establish that these data are confidential. Privacy and security considerations are integral to all procedural steps to assure confidentiality of information. Access to MBDR data is limited to essential registry personnel and other departmental staff whose programmatic use of the information has been approved by the Department director. Rules governing the MBDR specify the conditions and approval processes under which this information may be released.

## **Electronic Training Module**

A web-based training module was developed and implemented in January 2006 to assist staff in training facility personnel who submit case reports. The Birth Defects Registry online training course discusses the value of the MBDR and teaches individuals how to complete both the paper-based and electronic reporting forms. A link to the training module can be found at:  
<http://training.mihealth.org/coursedetail.htm>.

## **Quality Assurance**

Concurrent internal monitoring assures that incoming reports are screened for missing and invalid information as they are processed into the registry. MBDR staff compares demographic information on birth defects reports with birth and death records. They may contact reporting facility staff to correct and complete all data before they are linked with birth and death files. To further improve the accuracy and completeness of case ascertainment, the MBDR is linked with other public health program datasets. Linkages with the MBDR include: 1) data linkage with Children's Special Health Care Services Program (CSHCS); 2) case sharing of hearing loss diagnoses with the Early Hearing Detection and Intervention Program (EHDI); 3) acquiring confirmed cases from the Newborn Screening Program (NBS); 4) continued reporting from four pediatric genetics clinics; and 5) voluntary reporting from Fetal and Infant Mortality Review Program (FIMR). These linkages help to assure that the MBDR is as complete and accurate as possible.

Reporting facilities are monitored for method, accuracy, and completeness of case reporting. Unreported cases are identified and submitted to the MBDR. Subsequently, education and technical support are provided to ensure reporting facilities are in compliance with legislative mandates. Retrospective facility audits are conducted every three to four years to assess statewide performance in the reporting of birth defects and to identify opportunities for improvement. In the 1999 audit, 81.1% of the reported cases reviewed had information in the health record consistent with the information submitted to the registry, and in the 2003 audit, an accuracy rate of 95.0% was found for cases reviewed. The retrospective facility audit of 2006 admissions was conducted in 2009-2010. From this audit, about 18% of errors were demographic discrepancies and about 11% were diagnostic. A total of 33 false positives were found for a false detection rate of 6.0%. Following the audit, targeted training and technical assistance is given to participating facilities.

## MBDR Evaluation

Recommendations for state birth defects surveillance systems are put forth by the National Birth Defects Prevention Network (NBDPN), “Guidelines for Conducting Birth Defects Surveillance.”<sup>4</sup> An evaluation of the MBDR was conducted in 2005 to 2006, broadly following the “Updated Guidelines for Evaluation of Public Health Surveillance Systems.”<sup>5</sup> These guidelines suggest evaluation of the following system attributes: simplicity, flexibility, data quality, acceptability, sensitivity, positive predictive value (PPV), representativeness (how well cases reported represent the population as a whole), timeliness of reporting, and stability of the system over time.<sup>6</sup> More information on facility audits and the surveillance system evaluation can be found in prior MBDR reports: Birth Defects Prevalence and Mortality in Michigan, 1992-2002, and Birth Defects Prevalence and Mortality in Michigan, 1992-2003, available online by clicking on Statistics and Reports at: [www.michigan.gov/mchept](http://www.michigan.gov/mchept).

## FOLLOW-UP

An integral component of a comprehensive Birth Defects Surveillance Program is follow-up to ensure that children are connected with services and that the needs of families are met. The program strives to: 1) identify the special needs of children with birth defects, and 2) assure families are connected to resources and support systems. Providing information to families in a timely manner, while preserving the privacy of birth defects data, is a priority. Among the key needs identified by families of children with birth defects are medical information and services, family emotional and spiritual support, advocacy, and prevention information.

In 2004, the Birth Defects Program developed a follow-up plan for infants with neural tube defects (NTD) and their families. Additionally, registry data has been used to identify children with hearing loss through inter-program cooperation with the MDCH Early Hearing Detection and Intervention (EHDI) Program. A pilot project using MBDR data to identify children who might benefit from early intervention services and were not enrolled in *Early On*®, Michigan’s early intervention system for young children from birth to three years of age, was conducted in 2007. These types of activities make use of surveillance data to provide assistance to children and families.

From 2007-2010, staff provided genetics trainings to parents and health providers through the Michigan Family-to-Family Health Information & Education Center. To help all families of children with birth defects locate the resources they need, the program maintains a Genetics Resource Center that includes a support group directory, located at [www.MiGRC.org](http://www.MiGRC.org). A pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs*, is available at no cost to hospitals, health professionals, and



families. A virtual Birth Defects Referral Toolkit is available for health care providers. This toolkit contains comprehensive information about the resources and services available for families of children with birth defects and genetic conditions.



# Technical Notes and Definitions

## Technical Notes

### Important factors to consider when viewing MBDR data

- Analyses presented in the body of this report are based on cases reported to the MBDR with at least one reportable birth defect alone, by one year of age.
- Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident of Michigan at the time of birth. This enables the calculation of birth defects prevalence rates.
- Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.
- Conditions are reportable if identified within the first two years of a child's life.
- Diagnoses are coded using the 9th revision to the International Classification of Diseases—ICD-9-CM.
- Diagnostic Code Groupings used for congenital anomaly codes are those used by the Centers of Disease Control and Prevention (CDC).

### Case Ascertainment

The MBDR relies on a passive system of reporting. Birth defects cases are reported by independent sources, that is, medical facilities and laboratories. The medical information obtained in the form of a case report generally is accepted as reported. In an active surveillance system, the program staff investigates data sources, finding and confirming birth defects cases. More information about case ascertainment can be found in the National Birth Defects Prevention Network's (NBDPN) Guidelines for Conducting Birth Defects Surveillance.<sup>4</sup>



### Data Quality Considerations

- The increased numbers of children diagnosed with hearing impairment in evidence since 1997 is related directly to a rapid increase in screening of Michigan newborns for hearing loss by birthing hospitals.
- Increases in frequency of endocrine and metabolic disorders since 1998 are due to coordination of case reporting with the Newborn Metabolic Screening Program.
- A change in ICD-9-CM coding added unique codes for hypospadias and epispadias in October of 1996. This is the cause of the discontinuity in the reported frequencies for these conditions as listed under the diagnostic grouping "H04 Hypospadias and Epispadias (75261, 75262)".
- The data and analyses presented in this report are affected by three factors that impact data accuracy and comparability:

**\*Inconsistent or incomplete reporting:**

There is evidence that reporting of birth defects by some facilities is not complete. Very low birth defect frequencies and significant shifts in the number of reported cases can be expected where reporting problems exist. This fact can make comparing specific birth defects rates over time or between geographic regions problematic. MBDR quality assurance work, beginning in 1999, to identify and resolve problems of under-reporting, resulted in birth defects case counts increasing due to more consistent and more complete reporting by facilities.

**\*Over reporting:**

Hospitals may submit cases of reportable diagnostic conditions which are later ruled out in a child, but the original report is not corrected accordingly. This can cause an over count of the number of cases. This problem can be expected to vary by facility which, in turn, can lead to inflated birth defect frequencies and geographic variation in case frequency counts for those areas where such facilities are located.

**\*Resident interstate information exchange is lacking:**

There is presently no exchange of data with neighboring states on children born with birth defects. Thus, birth defects cases are unreported whenever a Michigan child is diagnosed with, or treated for, a birth defect in a facility not in Michigan. This problem will cause an undercount of the actual number of cases and can be expected to significantly affect the completeness of reports for counties whose residents commonly travel outside Michigan for their health care. Due to the lack of interstate resident information exchange, rates are calculated only for resident children who are also born in Michigan.

***Three factors that impact data accuracy and comparability are:***

- ✓ ***Inconsistent or incomplete reporting***
- ✓ ***Over reporting***
- ✓ ***Lack of interstate resident data exchange***

## Definitions

**Birth defect:** An abnormality of the body's structure or inherent function present at birth, whether the abnormality is detected at the time of delivery or at a later time. Some birth defects are minor while others are life-threatening. The causes of many birth defects are still unknown, but some birth defects are caused by genetic factors while others result from exposure to certain drugs, medications, or chemicals.

**Case:** The individual birth defect reported to the Michigan Birth Defects Registry by one year of age. See Appendix B for list of reportable conditions.

**Infant fatality rate:** The number of deaths by one year of age among those with a specific birth defect divided by the total number of births with the specific birth defect of interest, multiplied by 1,000.

**Mortality rate:** The number of deaths by one year of age divided by the total number of live births, multiplied by 1,000.

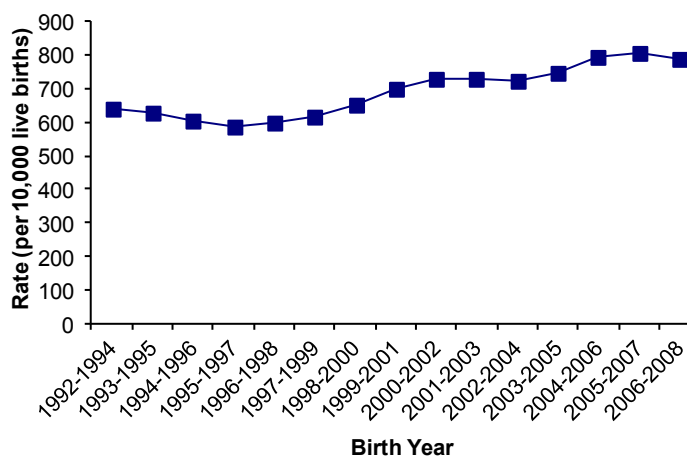
**Premature birth:** An infant who is born at less than 37 weeks of gestation.

**Prevalence rate:** The number of cases with a particular reportable birth defect divided by the total number of live births for the specific year of interest. This number is then multiplied by 10,000 to determine the rate per 10,000 live births.

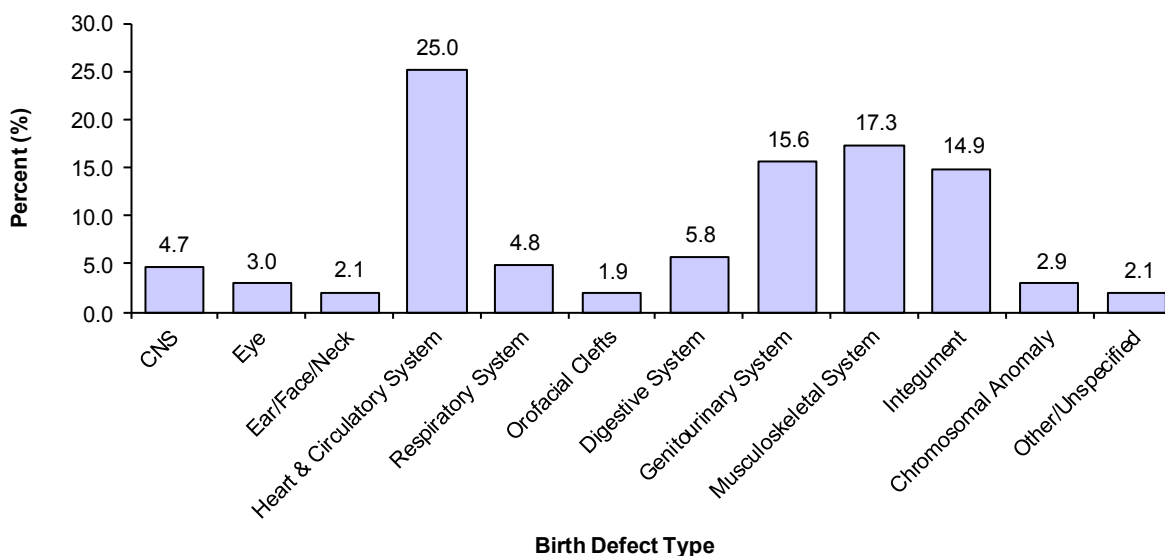


# Birth Defect Prevalence Trends

The overall prevalence rate of birth defects reported by one year of life has increased slightly over the past 16 years. There were about 650 reported defects per 10,000 live births in 1992 and 786 reported defects per 10,000 live births in 2008, as seen in Figure 1. This increase may in part be due to improved reporting and diagnostic techniques or to changes in population demographics. Population changes may include a shift in the distribution of births by maternal age or race, or a change in the rate of preterm infants. In 2008, the majority of reported birth defects fell into three diagnostic categories: the heart and circulatory system (25.0%), the musculoskeletal system (17.3%), and the genitourinary system (15.6%), as seen in Figure 2. Other birth defects fell into the integument (14.9%), digestive system (5.8%), the respiratory system (4.8%), and the central nervous system (CNS) (4.7%) categories. All other diagnostic categories had 3.0% or less of all reported birth defects. Categories are not mutually exclusive, meaning that an infant could be counted more than once if diagnosed with birth defects in multiple categories. This means that the numbers, and therefore rates, of specific types of birth defects may not reflect the rates of Michigan children with birth defects because some children have multiple defects and are therefore counted more than once by the MBDR.



**Figure 1:** Three year moving average of all birth defects reported by one year of age: MBDR, 1992-2008.

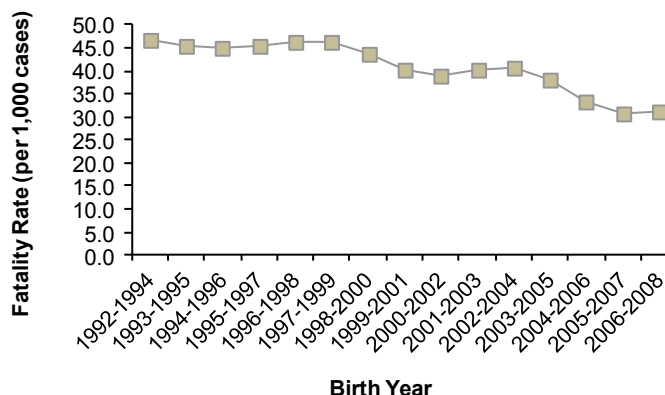


**Figure 2:** Distribution of birth defect categories in Michigan: MBDR, 2008.

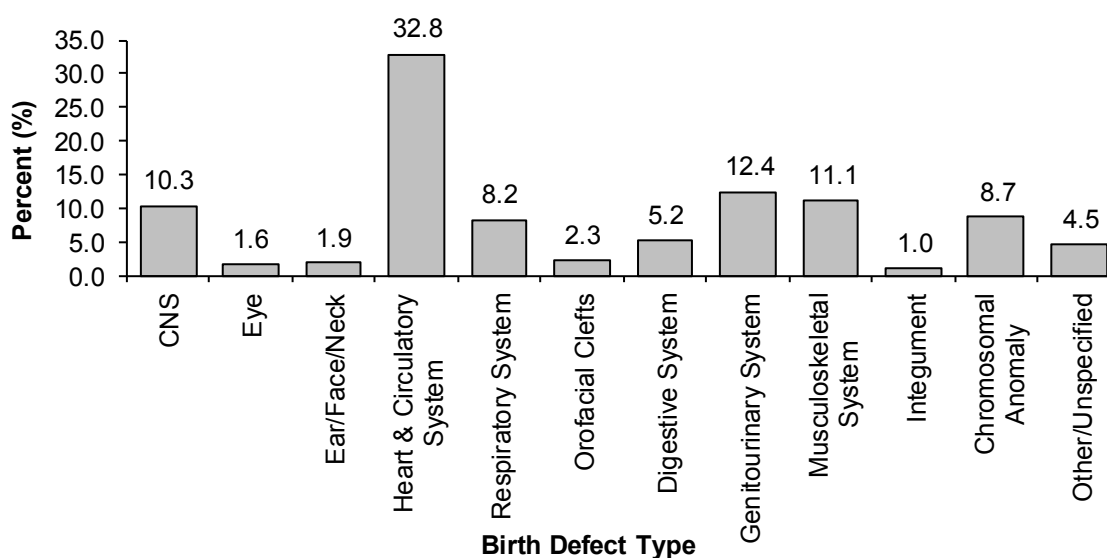
## Birth Defect Infant Fatality Trends

The overall infant fatality rate (deaths by one year of age) for all birth defects reported by one year of life has decreased over the past 16 years. The fatality rate is limited to the population reported to have a birth defect and is determined by dividing the number of deaths by the number of birth defects. There were about 47 deaths per 1,000 birth defect cases in 1992 and about 31 deaths per 1,000 defects in 2008, as seen in Figure 3. This decrease may in part be due to advances in medical care and improvements in surgical repairs of birth

defects.<sup>7</sup> In 2008, the majority of deaths among those with birth defects fell into three diagnostic categories: the heart and circulatory system (32.8%), the genitourinary system (12.4%), and the musculoskeletal system (11.1%), as seen in Figure 4. Other deaths among those with birth defects fell into the central nervous system (CNS) (10.3%), chromosomal anomalies (8.7%), the respiratory system (8.2%), the digestive system (5.2%), and some other or unspecified type of defect (4.5%) categories. All other diagnostic categories are less than 3.0% of all reported deaths by one year of age. Categories are not mutually exclusive, meaning that an infant could be counted more than once if diagnosed with birth defects in multiple categories. Infants with more severe or multiple defects may be at higher risk of dying within the first year of life.



**Figure 3:** Three year moving average of infant fatality rates for all birth defects reported by one year of age: MBDR, 1992-2008.



**Figure 4:** Distribution of deaths by birth defect categories in Michigan: MBDR, 2008.



## Selected Birth Defect Rates, 1992-2008

Prevalence rates of neural tube defects, orofacial clefts, chromosomal anomalies and congenital heart defects were analyzed by maternal age, maternal race and ethnicity, and sex of the infant. The three year moving prevalence rates were also calculated to assess trends over time. By analyzing birth defect rates stratified on a variety of factors, health disparities among certain populations can be assessed so that prevention, intervention, and special services can be targeted to high-risk populations. Data on prevalence and mortality rates for additional birth defects in Michigan in local communities and counties can be found online at [www.michigan.gov/mdch](http://www.michigan.gov/mdch). Requests for additional birth defects data can be made by contacting the MBDR registrar at: (517) 335-8677.

Of note, the race variable does not include ethnicity information such as Hispanic or Arab, and race categories can include individuals of any ethnicity. Rates were calculated for all children reported with at least one reportable birth defect by one year of age who were born in Michigan and whose mothers were residents of Michigan at the time of birth, from 1992 to 2008. An asterisk indicates that there were fewer than six cases reported during the specified time period. Rates of these selected defects by Michigan counties and regions approximating hospital-based pediatric specialty services areas can be found in Appendix E and F.

**Table 2:** Prevalence of selected birth defects in Michigan diagnosed by one year of age: MBDR, 1992-2008.

<b>Congenital Anomaly (ICD-9-CM)</b>	<b>Rate (per 10,000 live births)<sup>1</sup></b>
<b>Neural Tube Defects (740-742)</b>	<b>6.4</b>
Anencephaly (740.0, 740.1)	1.0
Spina bifida (without anencephaly) (741.0, 741.9, w/o 740.0, 740.1)	4.4
Encephalocele (742.0)	1.1
<b>Orofacial Clefts (749)</b>	<b>15.7</b>
Cleft palate without cleft lip (749.0)	5.7
Cleft lip/palate (749.1, 749.2)	10.0
<b>Trisomy 13 (758.1)</b>	<b>1.0</b>
<b>Trisomy 18 (758.2)</b>	<b>1.3</b>
<b>Trisomy 21 (758.0)</b>	<b>11.4</b>
<b>Congenital Heart Defects (745-747)</b>	<b>151.7</b>
Ventricular septal defect (745.4)	40.3
Atrial septal defect (745.5)	62.3
Hypoplastic left heart syndrome (746.7)	3.7
746.01, 746.1, 746.7, 747.41)	15.2

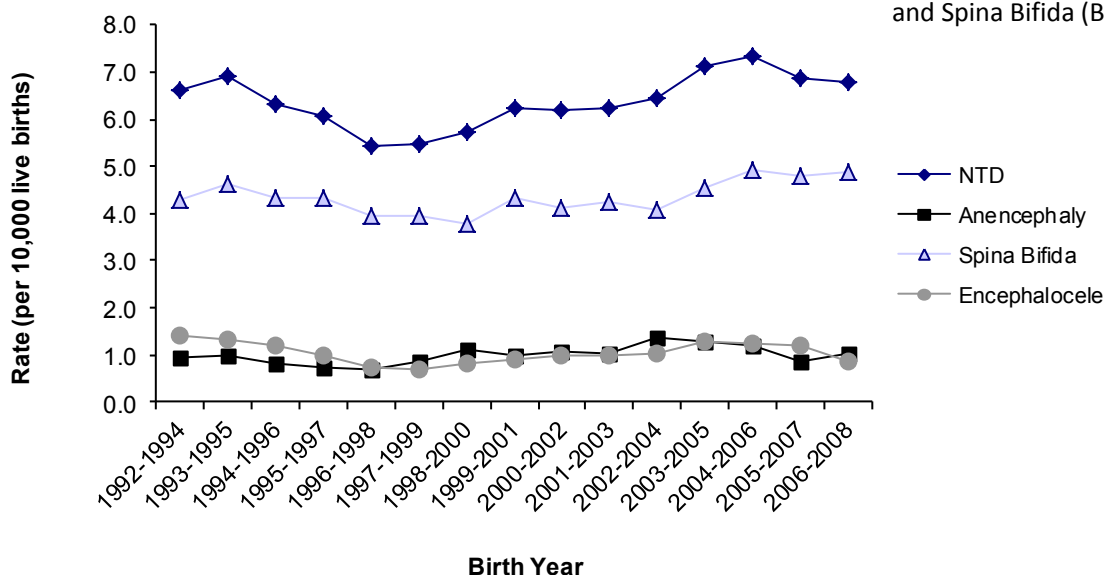
<sup>1</sup>Prevalence rates are based on resident occurrences. Data are current through August, 2010

## Neural Tube Defect (NTD) Prevalence

NTD are serious and often lethal birth defects of the brain and spine that occur during the first 28 days after conception when the neural tube is closing. Anencephaly is a fatal anomaly in which the neural tube fails to close. The brain does not develop properly and may be essentially absent. Spina bifida is the more common form of NTD in which the lower end of the neural tube fails to close, resulting in problems with development of the vertebrae and spinal cord. Encephalocele results from an opening in the skull associated with a skin covered sac-like structure containing central nervous system (brain) tissue or spinal fluid. It is usually fatal but babies who do survive typically have severe mental impairment. To help prevent NTD, the Centers for Disease Control and Prevention (CDC) encourages all women to consume at least 400 micrograms of folic acid every day before and during pregnancy.<sup>8</sup>



**Figure 5:** NTD: Anencephaly (Top), Encephalocele (Middle), and Spina Bifida (Bottom).<sup>9</sup>



**Figure 6:** Three year moving prevalence rates of neural tube defects: MBDR, 1992-2008.

From 1992 to 2008, the overall rate of NTD was 6.4 cases per 10,000 live births. The NTD rate remained relatively stable from 1992 to 2008, ranging from about 6.5 to 7.0 cases per 10,000 live births, with a slight increase in 1998 (Figure 6). This slight increase may be due to improved reporting and tracking of NTD. Rates of spina bifida remained stable over the last 16 years at about 4.5 cases per 10,000 live births. Both encephalocele and anencephaly remained stable from 1992 to 2008 at about one case per 10,000 live births for each type of defect.

**Table 3:** Prevalence rate of neural tube defects stratified by selected demographic variables: MBDR, 1992-2008.

Demographic Variable	Prevalence <sup>1,2</sup>			
	Total Neural Tube Defect	Anencephaly	Spina bifida	Encephalocele
<b>Total</b>	<b>6.4</b>	<b>1.0</b>	<b>4.4</b>	<b>1.1</b>
<b>Maternal Age</b>				
<20	6.9	1.1	4.3	1.5
20-24	6.5	1.1	4.2	1.2
25-29	6.5	1.0	4.6	0.9
30-34	5.6	0.7	4.0	0.8
35+	6.4	0.7	4.7	1.0
<b>Maternal Race</b>				
Whites	6.4	0.9	4.5	1.0
Blacks	6.2	0.8	3.7	1.6
Other <sup>3</sup>	4.6	0.5	3.9	*
<b>Maternal Ethnicity</b>				
Hispanic	6.6	0.9	4.5	1.3
Arab	3.5	1.1	2.5	*
<b>Gestational Age</b>				
<37 weeks	18.2	5.2	9.4	3.7
37+weeks	4.8	0.4	3.7	0.7

<sup>1</sup>Prevalence rates are based on resident occurrences. Data are current through August 2010.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births.

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

Overall, infants born to mothers less than 20 years old had a slightly higher rate of NTD with 6.9 cases per 10,000 live births (Table 3). Infants born to mothers who were 30-34 years old had lower rates of all neural tube defects, with about 5.6 cases per 10,000 live births, compared to about 6.5 cases per 10,000 live births in the other age groups.

The overall NTD rate was slightly higher in whites than in blacks (Table 3). The pattern is seen for all types of NTD except for encephalocele. Those in the category other race (not white or black) had a lower rate of NTD with 4.6 cases per 10,000 live births compared to about 6.3 cases per 10,000 live births for those who are white or black. Of note, the number of neural tube defects is very low (fewer than 5 cases from 1992 to 2008) for those of the other category, so rate calculations can be unstable. Spina bifida was more prevalent in whites than in blacks, while encephalocele was more prevalent in blacks than in whites.

Overall, the prevalence of NTD was higher in the Hispanic population than in the Arab population (Table 3). The rate of NTD among Hispanics was 6.6 cases per 10,000 live births while the rate of NTD among Arabs was 3.5 cases per 10,000 live births.

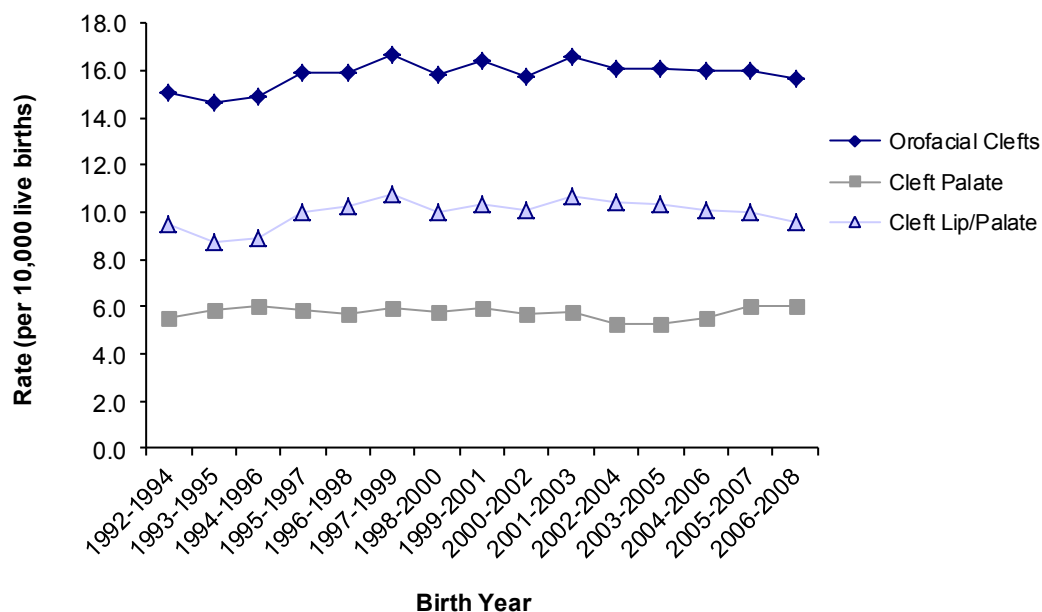
The prevalence of NTD was higher in those born premature (<37 weeks gestation) compared to those who were born at full term (18.2 per 10,000 live births compared to 4.8 per 10,000 live births, respectively) (Table 3). This trend was seen among all NTD subtypes.

## Orofacial Cleft Prevalence

An orofacial cleft is a separation or split in part of the face that should normally be closed or joined together. Clefts can occur in the developing lip, as well as in the hard and soft palate of the mouth. Two major categories of orofacial clefts are cleft lip with or without cleft palate, and isolated cleft palate. Orofacial clefts occur very early in embryonic development—by 5 to 6 weeks after conception for clefts of the lip and by 10 weeks for palate malformations. A cleft may affect only one side of the lip and/or palate (unilateral) or both (bilateral). It may also affect the way the nose is formed and/or extend into the gum or upper jawbone. Rarely, oblique, lateral transverse and complex facial clefts occur. Children with orofacial clefts usually undergo one or more surgical repairs early in life and may later need orthodontic care and speech therapy. They may also require special feeding techniques, and have a greater risk of ear infections. Babies with an orofacial cleft usually do not have other health problems unless the cleft is part of a genetic syndrome associated with other birth defects. Both genetic and environmental factors play a role in the etiology of orofacial clefting. Recent studies by the CDC indicate that maternal use of multivitamin with folic acid may reduce the risk of some orofacial clefts.<sup>10</sup>



**Figure 7:** Cleft Lip (Top) and Cleft Palate (Bottom).<sup>9</sup>



**Figure 8:** Three year moving prevalence rates of orofacial clefts: MBDR, 1992-2008.

Overall, from 1992 to 2008, the prevalence of orofacial clefts was 15.7 cases per 10,000 live births. Rates of orofacial clefts remained relatively stable from 1992 to 2008 at about 16 cases per 10,000 live births. Rates of each category of orofacial clefts also remained stable with about 6 cases of isolated cleft palate, and about 10 cases of cleft lip/palate per 10,000 live births (Figure 8). The prevalence rate of cleft lip with or without cleft palate was about twice the rate of cleft palate alone.

**Table 4:** Prevalence rate of orofacial clefts stratified by selected demographic variables: MBDR, 1992-2008.

Demographic Variable	Prevalence <sup>1,2</sup>		
	Total Orofacial Cleft	Cleft palate	Cleft lip/palate
<b>Total</b>	<b>15.7</b>	<b>5.7</b>	<b>10.0</b>
<b>Maternal Age</b>			
<20	16.9	5.9	11.0
20-24	17.1	5.5	11.6
25-29	14.7	5.9	8.8
30-34	14.9	5.5	9.4
35+	15.1	5.8	9.3
<b>Maternal Race</b>			
Whites	16.8	6.0	10.8
Blacks	10.6	4.5	6.1
Other <sup>3</sup>	15.5	5.2	10.3
<b>Maternal Ethnicity</b>			
Hispanic	12.9	3.5	9.4
Arab	8.2	4.1	4.1
<b>Gestational Age</b>			
<37 weeks	23.1	10.7	12.3
37+weeks	14.6	5.1	9.6

<sup>1</sup> Prevalence rates are based on resident occurrences. Data are current through August 2009.

<sup>2</sup> Prevalence rate expressed as cases per 10,000 live births.

<sup>3</sup> Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

Overall, orofacial clefts were more prevalent in infants born to younger mothers (less than 24 years old) (Table 4). For mothers who were 24 years of age or younger, the rate of orofacial clefts was 17.0 cases per 10,000 live births while for mothers older than 24, the rate was about 15 cases per 10,000 live births. This trend has also been seen at the national level by previous research.<sup>7</sup> In Michigan, the higher rate of orofacial clefts among younger mothers appears to be driven by rates of cleft lip with or without palate since the prevalence of cleft palate seems to be consistent across all maternal age categories.

The prevalence rate of orofacial clefts in whites was 16.8 cases per 10,000 live births, while blacks had a lower prevalence with 10.6 cases per 10,000 live births (Table 4).

Mothers of Hispanic ethnicity had a higher rate (12.9 cases per 10,000 live births) of orofacial clefts than those of Arab ethnicity (8.2 cases per 10,000 live births) (Table 4).

Orofacial clefts were slightly more common in those who were preterm than in those born full term with 23.1 cases per 10,000 live births in preterm infants and 14.6 cases per 10,000 live births in full term infants (Table 4). These patterns are found in rates for both cleft palate alone and cleft lip with or without cleft palate.

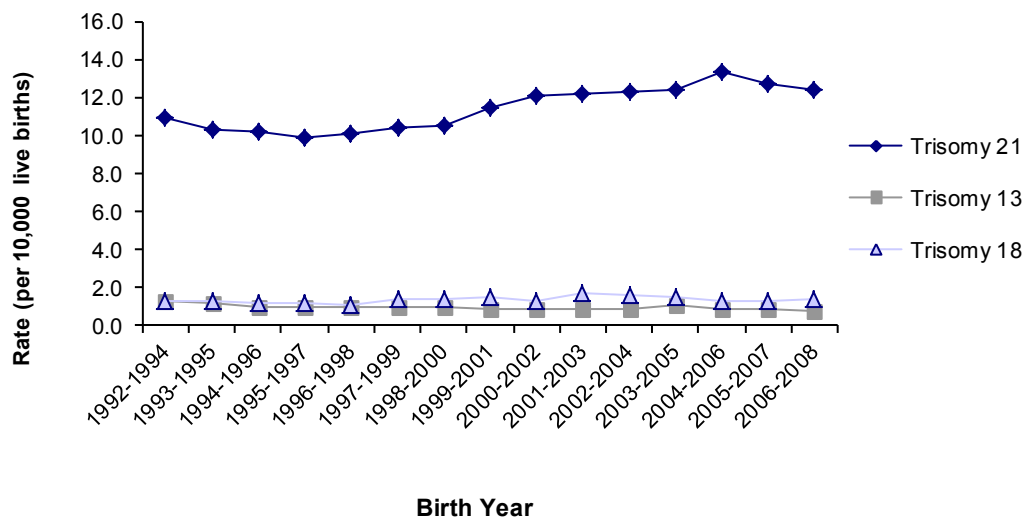
Cleft lip/palate and cleft palate alone may have different etiologies as evidenced by the disparity in cleft lip/palate rates and the relative consistency of the cleft palate rates across maternal age, maternal race, and maternal ethnicity.

## Chromosomal Anomaly Prevalence

In the United States, about 1 in 150 babies is born with a chromosomal abnormality each year. These abnormalities result in varying degrees of intellectual and physical disabilities, miscarriages, stillbirths, and death. Trisomies 13, 18 and 21 comprise the most common chromosomal abnormalities in full term infants. These conditions are caused by the presence of an extra copy of the chromosome for which they are named. Trisomies 13 and 18 occur less frequently and are more severe, typically fatal. Trisomy 21, also known as Down syndrome, is the most common chromosomal anomaly among live born infants. It is a lifelong condition caused by the presence of associated with varying degrees of cognitive impairment. About 50% of children with Down syndrome also have a congenital heart defect. Other characteristics may include a variety of physical signs such as particular facial features, digestive system problems, increased risk of infections as well as increased risk of hearing and vision problems. The most common known risk factor for Down syndrome is advanced maternal age (35 years of age or older).<sup>11</sup>



**Figure 9:** Down syndrome.<sup>9</sup>



**Figure 10:** Three year moving prevalence rates of Down syndrome, trisomy 13, and trisomy 18: MBDR, 1992-2008.

The overall rate of chromosomal anomalies from 1992 to 2008 were as follows: Down syndrome—11.4 cases per 10,000 live births; trisomy 13—1.0 cases per 10,000 live births; trisomy 18—1.3 cases per 10,000 live births. The rate of Down syndrome has been increasing since about 1999 (Figure 10). In 1992, there were about 11 cases of Down syndrome per 10,000 live births and in 2008 there were about 13 cases per 10,000 live births. Other chromosomal anomalies are much less prevalent than Down syndrome. Rates of trisomy 13 and trisomy 18 have remained relatively stable throughout the years.

**Table 5:** Prevalence rate of Down syndrome, trisomy 13, and trisomy 18 stratified by selected demographic variables: MBDR, 1992-2008.

Demographic Variable	Prevalence <sup>1,2</sup>		
	Trisomy 13	Down Syndrome	Trisomy 18
<b>Total</b>	<b>1.0</b>	<b>11.4</b>	<b>1.3</b>
<b>Maternal Age</b>			
<20	0.7	6.0	0.8
20-24	0.7	6.9	1.0
25-29	0.8	6.9	1.0
30-34	1.0	10.8	1.2
35+	1.7	37.1	3.2
<b>Maternal Race</b>			
Whites	0.9	12.0	1.2
Blacks	1.1	8.9	1.5
Other <sup>3</sup>	1.0	10.4	1.8
<b>Maternal Ethnicity</b>			
Hispanic	1.3	11.8	1.6
Arab	0.7	10.8	1.1
<b>Gestational Age</b>			
<37 weeks	3.7	25.4	4.6
37+weeks	0.6	9.6	0.9

<sup>1</sup> Prevalence rates are based on resident occurrences. Data are current through August 2009.

<sup>2</sup> Prevalence rate expressed as cases per 10,000 live births.

<sup>3</sup> Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

As seen in Table 5, the highest prevalence of Down syndrome, trisomy 13 and trisomy 18 was in infants born to women over 35, compared to all other age groups. Prevalence of Down syndrome differed more among age groups than other chromosomal anomalies. Prevalence of Down syndrome among those age 35 or older was 37.1 cases per 10,000 live births while prevalence among other age groups was as follows: 6.0 cases in women less than 20 years old, 6.9 cases in women 20-24 years old; 6.9 cases in women 25-29 years old, and 10.8 cases in women 30-34 years old, all per 10,000 live births.

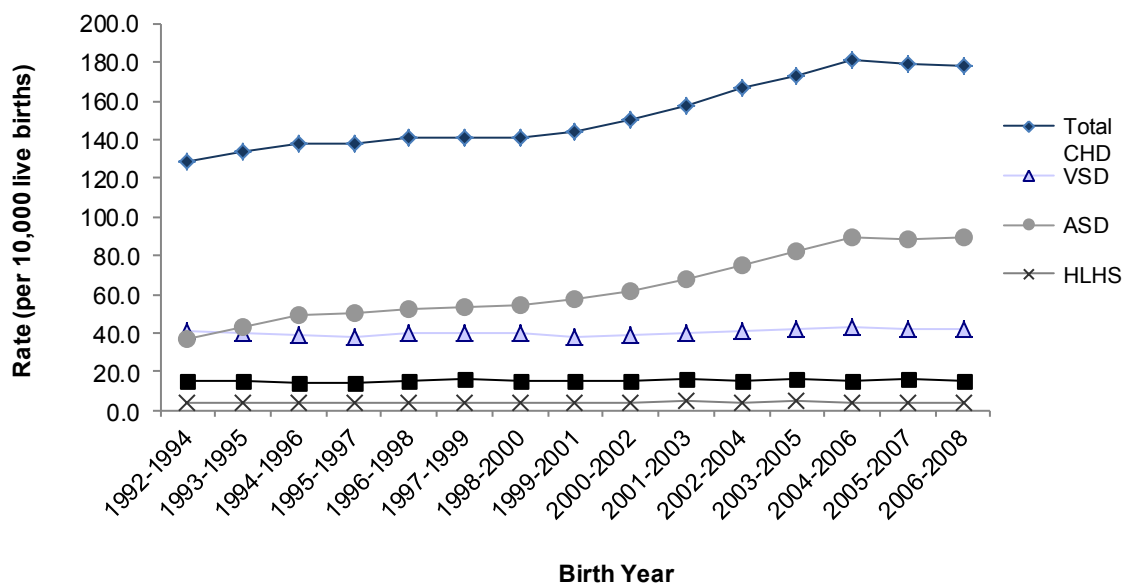
The prevalence of trisomy 13 and trisomy 18 were slightly higher among blacks, compared to whites, while prevalence of Down syndrome was lower in blacks with 8.9 cases per 10,000 live births, compared to whites with a prevalence of 11.8 cases per 10,000 live births (Table 5).

Those of Hispanic ethnicity had a higher prevalence rate of Down syndrome with 11.8 cases per 10,000 live births, compared to those of Arab ethnicity with 10.8 cases per 10,000 live births. Trisomy 13 and trisomy 18 were also more prevalent in Hispanic populations than among Arab populations (Table 5). Additional analyses of these populations should be performed to assess maternal age differences in order to help determine if this plays a role in the prevalence rate difference.

Preterm infants had higher prevalence of trisomy 13, Down syndrome, and trisomy 18. Prevalence of Down syndrome in preterm infants was 25.4 cases per 10,000 live births, compared to full term infants with 9.6 cases per 10,000 live births. Prevalence of trisomy 13 in preterm infants was 3.7 cases per 10,000 live births, compared to full term infants with 0.6 cases per 10,000 live births. Prevalence of trisomy 18 in preterm infants was 4.6 cases per 10,000 live births, compared to full term infants with 0.9 cases per 10,000 live births (Table 5).

## Congenital Heart Defects (CHD) Prevalence

Congenital heart defects (CHD) are one of the most common congenital anomalies. The heart begins to form at about 20 days after fertilization. CHD can occur at any stage of its development. Types of CHD range from minor conditions that may go undiagnosed for years to those that may cause death soon after birth. The most common types are ventricular septal defects (VSD) and atrial septal defects (ASD). Complex heart defects such as hypoplastic left heart syndrome (HLHS) are relatively rare. Critical congenital heart defects (CCHD) are a subgroup often described as ductal dependent and requiring surgery or catheterization in the first year of life. CCHD may be detected in the newborn period by pulse oximetry. This group typically includes: tetralogy of Fallot, D-transposition of the great arteries, truncus arteriosus, total anomalous pulmonary venous return, tricuspid atresia, pulmonary atresia, and hypoplastic left heart syndrome. The Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommends that all newborns be screened for CCHD, using pulse oximetry. Although the cause of about 85% of CHD is unknown, some genetic and maternal factors such as tobacco and alcohol use during pregnancy, obesity and diabetes, and some maternal infections and medications have been shown to be risk factors.<sup>12,13</sup> Analysis of ASD, VSD, HLHS and CCHD are included here with all CHD.



**Figure 11:** Three year moving prevalence rates of congenital heart defects: MBDR, 1992-2008.

The overall rate of CHD from 1992 to 2008 was 151.7 cases per 10,000 live births. Specific types of CHD had rates as follows: VSD—40.3 cases per 10,000 live births; ASD—62.3 cases per 10,000 live births; HLHS—3.7 cases per 10,000 live births; CCHD—15.2 cases per 10,000 live births. The overall rate of CHD has been increasing since about 1998 (Figure 11). In 1992, there were about 129 cases of CHD per 10,000 live births and in 2008 there were about 179 cases per 10,000 live births. In Michigan, the increasing rate of CHD appears to be driven by increasing rates of ASD. Some increase in CHD prevalence may be due to advances in technology and improved diagnostic techniques.<sup>14</sup> However, it is not clear whether it is improved diagnosis or other factors that explain the increase in ASD case



reports in Michigan. Prevalence of ASD increased from 37 cases per 10,000 live births in 1992 to 89 cases per 10,000 live births in 2008. Rates of VSD, HLHS and CCHD remained stable over the years.

**Table 6:** Prevalence rate of congenital heart defects stratified by selected demographic variables: MBDR, 1992-2008.

Demographic Variable	Prevalence <sup>1,2</sup>				
	Total CHD	VSD	ASD	HLHS	CCHD
<b>Total</b>	<b>151.7</b>	<b>40.3</b>	<b>62.3</b>	<b>3.7</b>	<b>15.2</b>
<b>Maternal Age</b>					
<20	148.4	34.4	59.5	2.5	13.3
20-24	143.1	34.6	59.2	3.7	14.7
25-29	142.9	39.2	58.1	3.8	14.8
30-34	150.6	41.9	61.7	3.9	15.4
35+	189.4	55.0	79.6	3.8	17.8
<b>Maternal Race</b>					
Whites	141.8	41.4	60.4	3.7	15.0
Blacks	194.3	34.4	71.1	3.7	15.4
Other <sup>3</sup>	120.1	37.9	48.2	3.0	12.8
<b>Maternal Ethnicity</b>					
Hispanic	128.3	35.6	59.8	2.5	13.2
Arab	146.8	43.6	66.0	3.4	14.4
<b>Gestational Age</b>					
<37 weeks	420.1	87.1	208.8	5.9	27.0
37+weeks	116.8	34.0	43.7	3.3	13.4

<sup>1</sup> Prevalence rates are based on resident occurrences. Data are current through August 2009.

<sup>2</sup> Prevalence rate expressed as cases per 10,000 live births.

<sup>3</sup> Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

All CHD, VSD, ASD and CCHD were more prevalent in infants born to older mothers (35 years or older) while HLHS was more prevalent in the infants of mothers who were 20 years or older (Table 6). Prevalence of CHD among those 35 years or older was about 190 cases per 10,000 live births compared to about 140 to 150 cases per 10,000 live births in all other age categories. Prevalence of VSD was about 55 cases per 10,000 live births in those 35 years or older and about 35 to 40 cases per 10,000 live births in other age categories. Prevalence of HLHS was 2.5 cases per 10,000 live births among those younger than 20 years while its prevalence among older groups was about 4 cases per 10,000 live births.

The prevalence rate of CHD in whites was 141.8 cases per 10,000 live births, while blacks had a higher prevalence with 194.3 cases per 10,000 live births (Table 6). Prevalence of VSD was higher among whites while prevalence of ASD was higher among blacks. Prevalence of HLHS and CCHD were similar among whites and blacks. Mothers of Hispanic ethnicity had a lower rate of CHD among their live born infants than those of Arab ethnicity (128.3 cases per 10,000 live births and 146.8 cases per 10,000 live births, respectively) (Table 6). Prevalence of VSD, ASD, HLHS and CCHD were all lower among the Hispanic population compared to the Arab population.

CHD were more prevalent in those who were preterm than in those born full term with 420.1 cases per 10,000 live births in preterm infants and 116.8 cases per 10,000 live births in full term infants (Table 6). This pattern was found among other categories of CHD, and has been reported nationally.<sup>15</sup>

# Fatality and Mortality Rates in Infants with Birth Defects, 1992-2008

The mortality experienced by Michigan children with birth defects is appreciably higher than for children in general. Birth defects registry data indicate that the contribution of birth defects to infant and childhood fatality is more than twice that indicated by cause of death data alone. The relative risk of death for children with birth defects is roughly five times that of other children. The elevated relative risk of death for children with birth defects is highest in children age one to two years old. Children with birth defects constitute 50% of the deaths in this age group, with relative risk of mortality that is about seven times the mortality rate of other children. Elevated mortality is experienced by children in the registry for all ages examined, including through the age of 16 years.

**Table 7:** Infant fatality and mortality rates for Michigan children with selected birth defects: MBDR, 1992-2008.

**Table 1:** Prevalence of selected birth defects in Michigan diagnosed by 1 year of age, 19

<b>Congenital Anomaly (ICD-9-CM)</b>	<b>Rate (per 10,000 live births)<sup>1</sup></b>
<b>Neural Tube Defects (740-742)</b>	<b>6.4</b>
Anencephaly (740.0, 740.1)	1.0
Spina bifida (without anencephaly) (741.0, 741.9, w/o 740.0, 740.1)	4.4
Encephalocele (742.0)	1.1
<b>Orofacial Clefts (749)</b>	<b>15.7</b>
Cleft palate without cleft lip (749.0)	5.7
Cleft lip/palate (749.1, 749.2)	10.0
<b>Trisomy 13 (758.1)</b>	<b>1.0</b>
<b>Trisomy 18 (758.2)</b>	<b>1.3</b>
<b>Trisomy 21 (758.0)</b>	<b>11.4</b>
<b>Congenital Heart Defects (745-747)</b>	<b>151.7</b>
Ventricular septal defect (745.4)	40.3
Atrial septal defect (745.5)	62.3
Hypoplastic left heart syndrome (746.7)	3.7
746.01, 746.1, 746.7, 747.41)	15.2

Infant *fatality* is defined as the number of deaths in the first year of life divided by the number of infants with a specific birth defect (and then multiplied by 1,000 to determine the rate per 1,000 infants). Table 7 shows the fatality rates in children born from 1992 to 2008 with neural tube defects, orofacial clefts, chromosomal anomalies and congenital heart defects. For infants with one or more reportable birth defect, the fatality rate was 39.6 deaths per 1,000 cases. This compares to the overall infant mortality rate for *all* resident infants of 8.4 deaths per 1,000 live births from 1992 to 2008. Fatality rates of these defects will be further assessed in the following pages.

## Neural Tube Defect (NTD) Fatality

The fatality rate in infants with NTD was 236.7 deaths per 1,000 cases of NTD and the mortality rate was 0.2 deaths per 1,000 live births from 1992 to 2008. Fatality associated with spina bifida is far less than fatality associated with anencephaly or encephalocele. Fatality rates of spina bifida decreased from 79.5 deaths per 1,000 cases in 1992 to 58.4 deaths per 1,000 cases in 2008 (Figure 12). Fatality rates of encephalocele decreased from about 300 deaths per 1,000 cases in 1992 to about 200 deaths per 1,000 cases in 2008. While anencephaly is uniformly fatal, reporting errors likely explain the rates presented here.

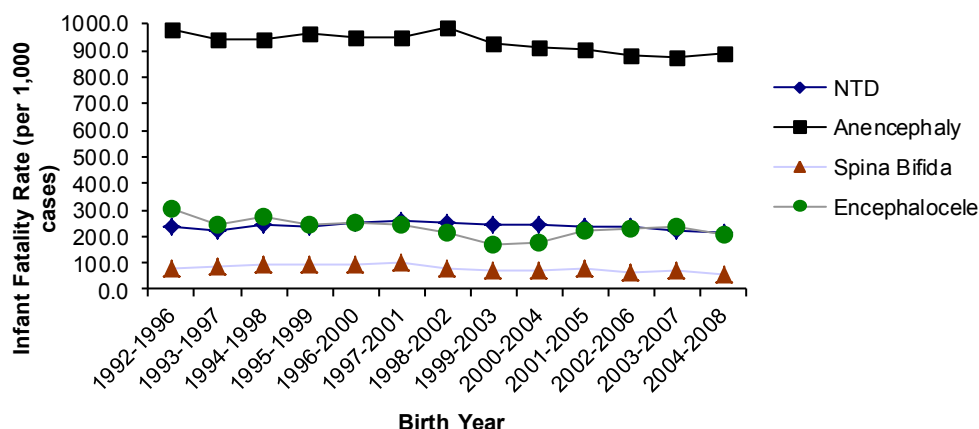


Figure 12: Five year moving infant fatality rates of neural tube defects: MBDR, 1992-2008.

## Orofacial Cleft Fatality

The orofacial cleft infant fatality rate was 63.5 deaths per 1,000 cases and the infant mortality rate was about 0.1 deaths per 1,000 live births from 1992 to 2008. The fatality rate of orofacial clefts decreased from about 70 deaths per 1,000 cases in 1992 to about 50 deaths per 1,000 cases in 2000 and increased to about 70 deaths per 1,000 cases in 2008 (Figure 13). This fluctuation in rates may in part be due to changes in the prevalence or reporting of syndromes that are associated with cleft lip and/or palate. Severity of each case is not known and infants may have more than one type of defect.

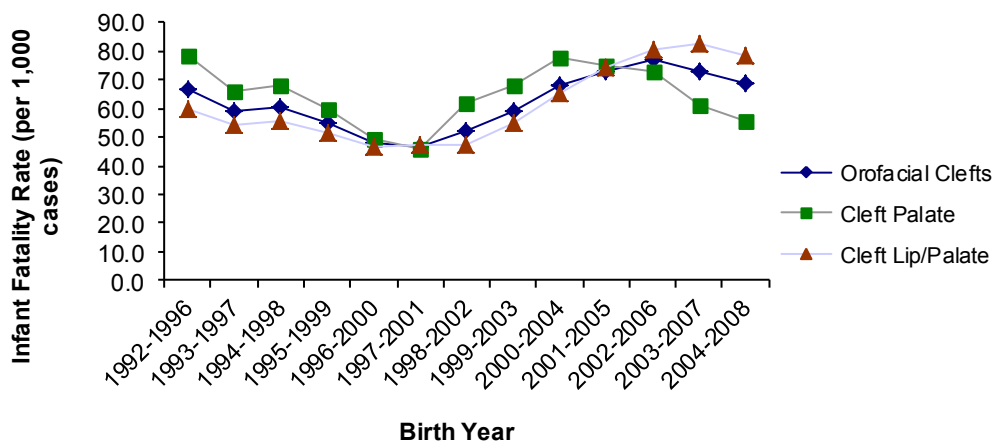
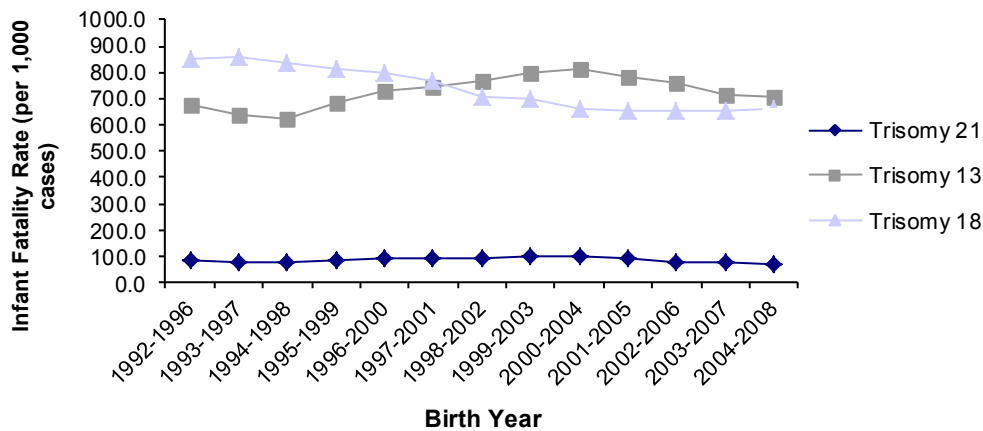


Figure 13: Five year moving infant fatality rates of orofacial clefts: MBDR, 1992-2008.

## Chromosomal Anomaly Fatality

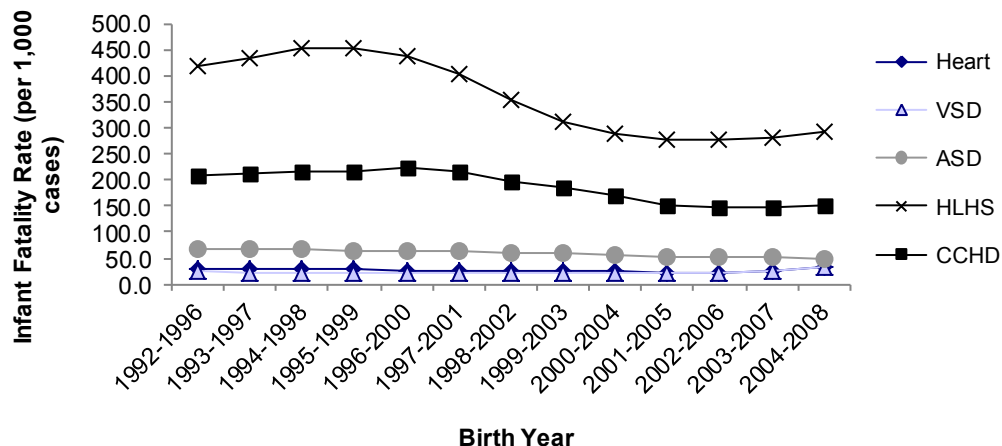
Trisomy 13 and trisomy 18 are more fatal than Down syndrome. Infant fatality rates were as follows: trisomy 13—714.9 deaths per 1,000 cases; trisomy 18—750.0 deaths per 1,000 cases; trisomy 21—83.5 deaths per 1,000 cases. Fatality rates of trisomy 18 decreased from 848.8 deaths per 1,000 cases in 1992 to 662.5 deaths per 1,000 cases in 2008 (Figure 14). Fatality rates of trisomy 13 increased from 679.0 deaths per 1,000 cases in 1992 to 709.1 deaths per 1,000 cases in 2008 (Figure 14). Fatality rates of trisomy 21 stayed relatively similar across the years.



**Figure 14:** Five year moving infant fatality rates of chromosomal anomalies: MBDR, 1992-2008.

## Congenital Heart Defect Fatality

The overall CHD infant fatality rate was 74.4 deaths per 1,000 cases and the mortality rate was 1.1 deaths per 1,000 live births. Hypoplastic left heart syndrome (HLHS) has higher fatality than other types of CHD. HLHS fatality rates decreased from about 420 deaths per 1,000 cases in 1992 to about 300 deaths per 1,000 cases in 2008 (Figure 15). Fatality rates of ventricular septal defect (VSD) remained at about 20 deaths per 1,000 cases and rates of atrial septal defect (ASD) remained at about 60 deaths per 1,000 cases throughout the years (Figure 15). Fatality rates of critical congenital heart defects (CCHD) decreased slightly from 207.9 deaths per 1,000 cases in 1992 to 151.1 deaths per 1,000 cases in 2008 (Figure 15).



**Figure 15:** Five year moving infant fatality rates of congenital heart defects (CHD): MBDR, 1992-2008.

The mortality of children in the registry is routinely monitored using a passive system of annual birth-death matching for all children in the registry. To examine the resulting data in a meaningful way, comparative data on the mortality of all Michigan children is also routinely developed. The result is a unique resource for studying the long-term effects of birth defects on infant and childhood health and survival. These data can be used to evaluate the risk of mortality for children with specific defects. Mortality rates and relative risk by age can also be monitored using this information, along with trends in mortality over time. Presently, the MBDR contains data on mortality in children through 16 years of age.

To help address birth defects as a cause of infant mortality, the Healthy People 2020 goal concerning infant mortality due to birth defects is to lower the rate to 1.3 deaths per 1,000 live births.<sup>16</sup> Michigan has not yet reached this goal, remaining at about 2.8 deaths per 1,000 live births from 1992 to 2008. Other Healthy People 2020 objectives are related to reducing infant

mortality due to congenital heart defects and Down syndrome. Michigan is currently not meeting the Healthy People 2020 target of 0.34 deaths per 1,000 live births among infants with congenital heart defects or the target of 43.7 deaths per 1,000 cases of Down syndrome.

Reducing overall infant mortality is one of Michigan's top priorities, as seen in the *Michigan Dashboard*, measuring Michigan's success with selected performance indicators. These indicators can be viewed at: <http://www.michigan.gov/midashboard/>.

High infant fatality rates among those with birth defects underscore the increased need for support experienced by so many of these families and children who have life-limiting conditions. Hospice and palliative care programs provide pain management, symptom control, psychosocial support, and spiritual care to patients and their families. They also serve as important sources of information about care options. Hospice and palliative care programs with a focus on pediatric care can be found throughout the state.

## **Healthy People 2020**

### **Maternal and Child Health Objectives and Indicators**

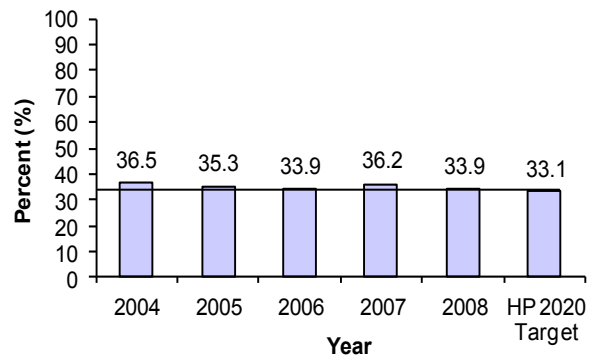
[HealthyPeople.gov](http://HealthyPeople.gov)

# A Closer Look: Healthy People 2020 Objectives

## Preconception Health and Behaviors

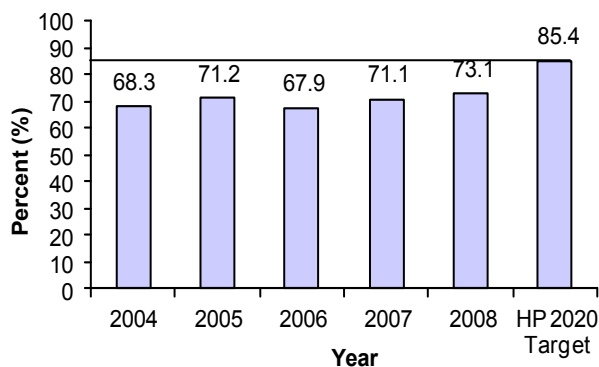
### Multivitamins / Folic Acid

- Women should consume at least 400 micrograms of folic acid each day before and during pregnancy to help reduce the risk of neural tube defects (NTD). Folic acid can be found in some multivitamins, leafy green vegetables, and in fortified foods (<http://www.cdc.gov/ncbddd/folicacid/>).
- **Healthy People 2020 goal:** 33.1% of women take a multivitamin/folic acid before pregnancy. Michigan has exceeded this goal over the past 5 years.
- **MI Birth Defect Program Activities:** Our program works with national, state and local partners to provide educational materials for women of childbearing age, participates in Folic Acid Awareness Week annually and supports provider awareness and education through newsletters, listservs, trainings, and [web content](#).



**Figure 16:** Percent of women with a live birth who took multivitamins at least four times a week in month prior to pregnancy: MI PRAMS, 2001-2008.

### Smoking



**Figure 17:** Percent of women with a live birth who did not smoke in the three months prior to pregnancy: MI PRAMS, 2001-2008.

- Smoking during pregnancy is a risk factor for some pregnancy and labor complications and adverse birth outcomes including premature birth and some birth defects, such as cleft lip or cleft palate (<http://www.cdc.gov/Features/PregnantDontSmoke/>). Women who quit smoking before becoming pregnant can prevent these effects.

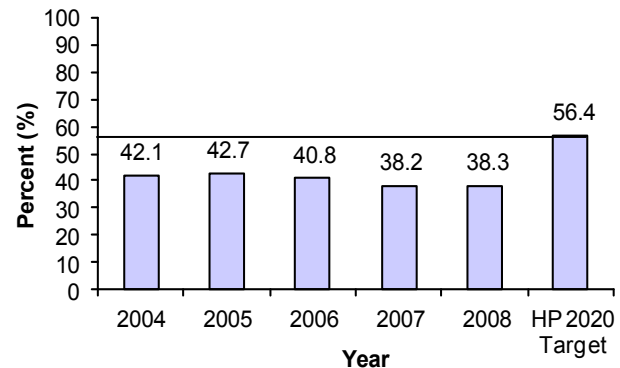
- **Healthy People 2020 goal:** 85.4% of women do not smoke in the three months prior to pregnancy. Michigan has not yet reached this goal, remaining at about 70% from 2004 to 2008.

- **MI Birth Defects Program Activities:** MBDR data has been linked to maternal and child data from the Michigan Special Supplemental

Nutrition Program for Women Infants and Children (WIC) to gain a better understanding of the occurrence of birth defects among the children of women who report smoking before and during pregnancy. We are partnering with WIC to offer professional training and develop strategies for targeted outreach.

## Alcohol Use

- The CDC urges women to refrain from drinking any amount of alcohol at any time during pregnancy. Alcohol use during pregnancy may cause fetal alcohol spectrum disorders (FASD). (<http://www.cdc.gov/ncbddd/fasd/alcohol-use.html>). FASD is 100% preventable by not drinking alcohol during pregnancy.
- **Healthy People 2020 goal:** 56.4% of women do not drink alcohol in the three months prior to becoming pregnant. Michigan has not yet reached this goal, remaining at about 40% throughout the past years.

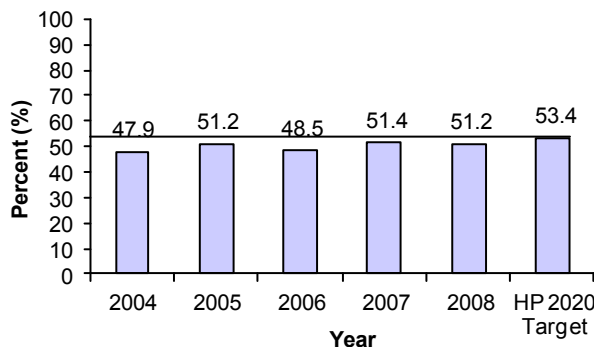


**Figure 18:** Percent of women with a live birth who did not drink alcohol in the three months prior to pregnancy: MI PRAMS, 2001-2008.

### MI Birth Defects Program Activities:

The Michigan Birth Defects Registry is working with the MDCH FASD Prevention Program and clinical diagnostic sites to improve surveillance. The program also participates on the MI FASD Taskforce and works to promote awareness among professionals and the public through trainings, publications and web content.

## Pre-Pregnancy BMI



**Figure 19:** Percent of women with a live birth who have a normal weight (BMI=18.5-24.9) prior to pregnancy: MI PRAMS, 2001-2008.

- It is important to have a healthy weight before becoming pregnant. Women who are overweight or obese before becoming pregnant are more likely to have an infant with a birth defect, such as a neural tube defect (NTD).<sup>17</sup> Moreover, women who are underweight before becoming pregnant are more likely to have an infant with gastroschisis.<sup>18</sup>

- **Healthy People 2020 goal:** 53.4% of women have a healthy weight before pregnancy. Michigan has yet to meet this goal, having had about 50% of women with a normal weight (BMI: 18.5-24.9) before becoming pregnant from 2005 to 2008.

### MI Birth Defects Program Activities:

Analysis of MBDR data found a higher prevalence of birth defects among babies born to women who were either obese or underweight, according to BMI. See more in the Michigan Monitor, [Spring 2011 Issue](#). Analysis of MBDR data linked to WIC data showed that women who were obese were more likely to have had a child with a birth defect. We are partnering with the Michigan WIC Program to provide professional training and develop strategies for targeted outreach.

# Studies and Publications (2010-2011)

## Presentations

Schierbeek B, Ehrhardt J, Langbo C, Bach J, Grigorescu V. Clinical genetic services: a view from Michigan's Children's Special Health Care Services' (CSHCS) families. Poster—National Birth Defects Prevention Network Annual Meeting, National Harbor, MD. March 2010. Poster—Michigan Epidemiology Conference, E. Lansing, MI. March 2010.

Schierbeek B, Ehrhardt J, Bach J, Grigorescu V. Teens with diabetes mellitus: promoting preconception care to prevent adverse pregnancy outcomes. Poster—National Birth Defects Prevention Network Annual Meeting, National Harbor, MD. March 2010. Poster—Healthy Mothers, Healthy Babies Conference, Mt. Pleasant, MI. June 2010.

Reimink B, Kleyn M, Grigorescu V. Identification of birth defects with sickle cell disease and sickle cell trait: MI NBS and MBDR data, 2004-2006. Oral—16<sup>th</sup> Annual MCH Epidemiology Conference, San Antonio, TX. December 2010.

Reimink B, Ehrhardt J, Grigorescu V. Investigation of a reported cluster of congenital heart defects in Midwest Michigan. Poster—2011 Annual CSTE Conference, Pittsburgh, PA. June 2011.

Reimink B, McKane P, Ehrhardt J, Eghtedary K, Grigorescu V. Impact of pre-pregnancy BMI on birth defects: MI WIC and MBDR data linkage, 2003-2007. Poster—2011 Maternal and Child Health Epidemiology Conference, New Orleans, LA. December 2011.

## Articles

Yanni EA, Copeland G, Olney RS. Birth defects and

genetic disorders among Arab Americans--Michigan, 1992-2003. J Immigr Minor Health. 2010 Jun;12(3):408-13.

Hirsch JC, Copeland G, Donohue JE, Kirby RS, Grigorescu V, Gurney JG. Population-based analysis of survival for hypoplastic left heart syndrome. J Pediatr. 2011 Jul;159(1):57-63.

Green RF, Ehrhardt J, Ruttenber MF, Olney RS. Use of family history information for neural tube defect prevention: integration into state-based recurrence prevention programs. Am J Health Educ. 2011; 43(5):296-308.

## Newsletters

Reimink B, Ehrhardt J, Bach J, Grigorescu V. Michigan Department of Community Health. Michigan Monitor. Volume 4, Issue 1. Spring 2010. —**Health Disparities in CHD**

Reimink B, Ehrhardt J, Bach J. Michigan Department of Community Health. Michigan Monitor. Volume 4, Issue 2. Summer 2010.—**Hearing Loss**

Reimink B, Ehrhardt J, Grigorescu V, Bach J. Michigan Department of Community Health. Michigan Monitor. Volume 5, Issue 1. Spring 2011. —**Maternal Obesity**

Reimink B, Ehrhardt J, Bach J. Michigan Department of Community Health. Michigan Monitor. Volume 5, Issue 2. Summer 2011.—**Infant & Childhood Mortality**

## Cluster Investigation

Reimink B, Ehrhardt J, Bach J, Grigorescu V. Congenital Heart Defects in Newaygo County: Cluster Investigation Report. Michigan Department of Community Health. December 2010.



# State and National Resources

*After the birth or adoption of a child with special needs, parents sometimes have questions. There are many programs in Michigan available free of charge. Many programs are run by parents who want to share information.*

## Family Support

**The Birth Defects Follow-up Program** at the Michigan Department of Community Health (MDCH) helps with referrals for support and services. The program provides resource information for families and health care providers. To speak with the follow-up coordinator or receive materials, call toll-free (866) 852-1247, e-mail [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov) or visit [www.MiGRC.org](http://www.MiGRC.org).

Families of children with all types of special needs share information and support in the **Family Support Network of Michigan**. To contact the network, call the Children's Special Health Care Services (CSHCS) Family Phone Line at (800) 359-3722.

The purpose of the Michigan **Family to Family Health Information Education Center (F2FIEC)** is to improve access to quality care and support for children with special needs in their communities by empowering families ([www.bridges4kids.org/f2f](http://www.bridges4kids.org/f2f)). The **Family Center** is a section of Children's Special Health Care Services (CSHCS). For details, phone the CSHCS Family Phone Line at 1-800-359-3722.

**Bridges4Kids** is a parent organization providing a comprehensive system of information and referral for parents of all children from birth to adult life with a special focus on those who have disabilities, special needs, or who are at-risk. For more information visit [www.bridges4kids.org](http://www.bridges4kids.org).

**Family Support Services** are offered through local community mental health agencies. Case management can help arrange services. Behavior intervention, family skills development, and respite care services are also available. Through respite care, families get a short break from caring for a child with special needs. To apply for family support services, call your local **Community**

**Mental Health Services Program** listed in the business section or yellow pages. If you need help finding the telephone number, call the Michigan Association of Community Mental Health Boards at (517) 374-6848.

**Parent HELpline** is a service of Gateway Community Services, funded by the Department of Human Services. It is available to anyone who needs help right away. The HELpline is open 24 hours a day, seven days a week. Trained counselors provide crisis counseling, support and information. The free, confidential number is (800) 942-HELP.

**Michigan Alliance for Families** provides information, support and education for families who have children (birth through 26 years of age) who receive or may be eligible to receive special education services. Call toll free (800)552-4821 or e-mail [info@michiganallianceforfamilies.org](mailto:info@michiganallianceforfamilies.org).

**Children's Special Health Care Services (CSHCS)** is a program that helps to coordinate and pay for hospital and outpatient medical *specialty* care. Help may also be available for travel expenses related to a child's medical care. More than 2,000 diagnoses are eligible for coverage. For more information about CSHCS call (800) 359-3722. Children with developmental disabilities who reside with their birth or adoptive parents and are in need of intensive community living supports and/or private duty nursing services may be eligible for the **Children's Waiver Program**. Contact your local Community Mental Health Services Program directly for more information. Call (517) 374-6848.

## Special Products

Advances in technology and new products help many children with special needs. **Michigan's Integrative Technology Supports (MITS)** has product information from more than 3,000

companies. Staff can help you find adaptive devices, special toys, clothing, equipment, and much more. Call (517) 908-3930, or see [www.mits.cenmi.org](http://www.mits.cenmi.org).

## Early Intervention

One of the most important support systems for young children with special needs is called **Early On® Michigan**. It provides services for eligible children from birth to age three and their families regardless of income. Examples of included services are: occupational, physical and speech therapy. For more information, call (800) EARLY-ON (800-327-5966) voice and (517) 668-2505 TTY; or visit [www.1800EarlyOn.org](http://www.1800EarlyOn.org).

## Special Education

Special education may help children who have physical, emotional, or mental conditions that prevent them from keeping up with others their age. Many services are offered free of charge by your public school system. **Project Find** helps to arrange a free evaluation through the local school district for any child who might need special education. For more information, call (800) 252-0052 or visit [www.projectfindmichigan.org](http://www.projectfindmichigan.org).

The **Center for Educational Networking** responds to the information needs of families, educators, and others who have a vested interest in the education of individuals with disabilities. Visit [www.cenmi.org](http://www.cenmi.org) to view the Michigan directory of services providers for infants, toddlers, and students with disabilities or call (888) 463-7656.

## Financial Support

*State and federal programs provide financial support to many families based on the child's diagnosis and family income.*

**Supplemental Security Income (SSI)** is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional and physical disabilities. The family income must meet certain guidelines. To find out more, call the Social Security Administration at (800) 772-1213.

The **Family Support Subsidy Program** provides monthly payments to some families whose child is severely mentally or multiply impaired, or autistic. To apply for the **Family Support Subsidy Program**, call your local Community Mental Health Services Program. For the number, call (517) 374-6848.

The **Children with Special Needs Fund** provides funds for equipment such as therapeutic tricycles or wheelchair ramps when there is no other source of payment. Families with a child medically eligible to enroll in Children's Special Health Care Services (CSHCS) may apply at their local health department or by calling (800) 359-3722 or (517) 241-7420.

## Genetic Counseling

Genetics clinics help families find out about a child's diagnosis. They answer questions about what to expect in the future and if the same condition could affect other people in the family. The MDCH **Genetics Program** has information about genetics clinics in the state. Call 1-866-852-1247 or visit [www.MiGRC.org](http://www.MiGRC.org) for more information.

## Newborn Screening

Newborn babies in Michigan are screened for more than 50 rare, but treatable, disorders. Michigan's **Newborn Screening (NBS) Follow-up Program** at the Michigan Department of Community Health (MDCH) assures that all newborns are screened and that infants with positive tests receive confirmatory diagnosis and treatment. For more information about newborn screening in Michigan, including updates for hospitals and information for parents, visit [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening).

The **Early Hearing Detection and Intervention (EHDI) Program** is a part of the Michigan Department of Community Health and works with hospitals and clinics to assure statewide screening of newborns for hearing loss and to build a statewide system for newborn hearing services. Please visit [www.michigan.gov/EHDI](http://www.michigan.gov/EHDI) for more

## National Organizations

*Information about many different conditions, even rare ones, is available from national support organizations and information centers.*

To find out if there is a national group that deals with a child's diagnosis, call the **Genetic Alliance** at (202) 966-5557, or see [www.geneticalliance.org](http://www.geneticalliance.org).

The **MUMS: National Parent-to-Parent Network** connects families of children who have a rare diagnosis. Visit [www.netnet.net/mums](http://www.netnet.net/mums).

The **National Dissemination Center for Children with Disabilities (NICHCY)** is a clearinghouse that offers information, referral, and free publications to families of children with special health needs. Call (800) 695-0285, or see [www.nichcy.org](http://www.nichcy.org).

The **National Organization for Rare Disorders (NORD)** is dedicated to helping people with rare "orphan" diseases that affect only a small number of people. Call (800) 999-6673, or see [www.rarediseases.org](http://www.rarediseases.org) to access this information clearinghouse.

The **Fathers Network** celebrates and supports fathers and families raising children with special health care needs and developmental disabilities. For more information call (425) 653-4286, or see [www.fathersnetwork.org](http://www.fathersnetwork.org).

## Birth Defects Prevention Resources

The Michigan Department of Community Health's (MDCH) **Prenatal Smoking Cessation (PSC) Program** is designed for pregnant smokers who are receiving health services in prenatal programs. The intervention model, "Smoke Free for Baby and Me", assesses the readiness to quit smoking and delivers clear, strong, personalized, and consistent intervention messages to support smoking cessation. The intervention is easily integrated into other medical, health and support services. For more information call (517)-335-9750.

The goal of the MDCH **Fetal Alcohol Syndrome**

**(FAS) Prevention Program** is to reduce the number of children born in Michigan with FAS, to provide timely diagnosis, and to assist those that are diagnosed with needed support services. Targeting women of childbearing age, education is offered at substance abuse treatment centers. Children identified with poor growth, learning disabilities or behavioral problems are targeted for screening, diagnosis and support. For more information, visit: [www.michigan.gov/fas](http://www.michigan.gov/fas).

The National Center on Birth Defects and Developmental Disabilities at the **Centers for Disease Control and Prevention (CDC)** offers a wide range of resources for families and professionals including the ABCs of having a healthy baby, basic facts about birth defects, birth defects research, folic acid promotion and fetal alcohol spectrum disorder. Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) for more information.

The mission of the **March of Dimes Birth Defects Foundation** is to improve the health of babies by preventing birth defects and infant mortality. Please visit [www.marchofdimes.com](http://www.marchofdimes.com) for a wealth of information on folic acid, prevention of prematurity, birth defects and genetics, and preparing for pregnancy.

The **National Birth Defects Prevention Network (NBDPN)** is a network of birth defects programs and individuals working at the local, state, and national level in birth defects surveillance, research and prevention. See [www.nbdpn.org](http://www.nbdpn.org) for annual 'Birth Defects Prevention Month' materials, surveillance reports and NTD/folic acid information.

Additional information and *free* educational resources on folic acid are available from the **CDC** at [www.cdc.gov/ncbddd/folicacid](http://www.cdc.gov/ncbddd/folicacid) and **Folicacid.net** at [www.folicacid.net](http://www.folicacid.net)

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# Appendices

- A. Birth Defects Program Fact Sheet
- B. Reportable Conditions by Diagnostic Group
- C. Hospital Birth Defects Reporting Form
- D. Cytogenetic Laboratory Birth Defects Reporting Form

MBDR Data, 1992-2008

**Figure 1:** Geographic regions approximate pediatric specialty care service areas.

**Table 1:** Prevalence of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2006.

**Table 2:** Infant fatality of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2008.

Mapping of Birth Defects by County, 1992-2008

**Figure 1:** Prevalence of neural tube defect (NTD) by county: MBDR, 1992-2008.

**Figure 2:** Prevalence of orofacial clefts (lip and/or palate) by county: MBDR, 1992-2008.

**Figure 3:** Prevalence of Chromosomal anomalies by county: MBDR, 1992-2008.

**Figure 4:** Prevalence of congenital heart defects (CHD) by county: MBDR, 1992- 2008.



# Birth Defects Prevention, Monitoring & Follow-up

*The three key components of the Birth Defects Program.*

## » Prevention «

*Identifying preventable birth defects and educating communities and professionals about prevention strategies.*

Certain maternal illnesses, infections, or exposures, such as alcohol, can cause birth defects that are potentially preventable.

MDCH works with many prevention partners including the March of Dimes, Healthy Mothers, Healthy Babies, reproductive genetic centers, and the National Birth Defects Prevention Network.

Highlights include:

- Promoting national Birth Defects Prevention Month in January.
- Informational materials including *Look and Feel Your Best with Folic Acid*, and *Preventing Birth Defects—Important Information for Michigan Families*.
- Conducting outreach to populations at risk, such as teen women with diabetes mellitus.

For information on folic acid and birth defects prevention, contact:

Joan Ehrhardt, Coordinator

Call: toll-free at 1-866-852-1247

Visit: [www.migeneticsconnection.org](http://www.migeneticsconnection.org)  
[www.michigan.gov/genomics](http://www.michigan.gov/genomics)

E-mail: [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov).

## » Monitoring «

*Building the foundation of information to improve understanding and care.*

The Michigan Birth Defects Registry (MBDR) was established in 1992 by state law.

- The MBDR monitors over 1,000 types of birth defects and contains reports on about 200,000 children.
- The confidential registry relies mainly on reports submitted by hospitals and laboratories and is supplemented by sources that serve children with special health needs and pediatric genetic clinics.
- About 10,000 Michigan children with birth defects are reported each year.
- Conditions include structural birth defects, genetic disorders and other conditions present at birth and identified by 24 months of age.
- MBDR data are analyzed by an epidemiologist to track the rate of birth defects, measure efforts to prevent birth defects and help Michigan communities evaluate and improve state services for children and families.

Statistical birth defect data can be found at:  
[www.mdch.state.mi.us/phal/osr](http://www.mdch.state.mi.us/phal/osr)

Reporting information and forms at:  
[www.michigan.gov/mbdr](http://www.michigan.gov/mbdr)

For questions contact:  
Glenn Copeland, MBDR Director  
Phone: (517) 335-8678

## » Follow-up «

*Understanding the special needs of children with birth defects and linking their families to resources and support systems.*

Established to help Michigan families obtain information, services, and support, the program provides a:

- Genetic support group directory online at [www.MIGeneticsConnection.org](http://www.MIGeneticsConnection.org).
- Pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs* at no charge to hospitals, health professionals and families.
- Birth Defects Resource Toolkit that includes a *Hospital Referral Guide* for healthcare providers, the *Special Care for Special Kids* guide for families and many other resources.
- Partnership in the Family-to-Family Health Information and Education Center established by the Family Center for Children and Youth with Special Health Needs.

To find information on services for children with birth defects, contact:

Joan Ehrhardt, Coordinator

Call: toll-free at 1-866-852-1247

Visit: [www.migeneticsconnection.org](http://www.migeneticsconnection.org)  
[www.michigan.gov/genomics](http://www.michigan.gov/genomics)

E-mail: [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov).

## Appendix B

	Conditions Reportable to the Michigan Birth Defects Registry
A	Congenital Anomalies of the Central Nervous System (740-742)
B	Congenital Anomalies of the Eye (743)
C	Congenital Anomalies of the Ear, Face and Neck (744)
D	Congenital Anomalies of the Heart and Circulatory System (745-746)
E	Congenital Anomalies of the Respiratory System (747-748)
F	Cleft Palate and Cleft Lip (749)
G	Congenital Anomalies of the Upper Alimentary Canal/Digestive System (750-751)
H	Congenital Anomalies of the Genital and Urinary Systems (752-753)
I	Congenital Anomalies of the Musculoskeletal System (754-756)
J	Congenital Anomalies of the Integument (757)
K	Chromosomal Anomalies (758)
L	Other and Unspecified Congenital Anomalies (759)
M	Infectious Conditions Occurring in the Perinatal Period (09.00-096.09, 771.0-771.2)
N	Familial/Congenital Neoplasms (237.70-237.72)
O	Endocrine/Metabolic Disorders (243, 252.00-252.08, 252.1, 253.2, 253.8, 255.2, 255.8, 257.8, 259.4, 270.0-273.9, 275.3, 277.0-277.9, 279.11, 279.2)
P	Diseases of the Blood and Blood Forming Organs (282.0-282.9, 284.0, 286.0-286.9, 287.3)
Q	Other Diseases of the Central and Peripheral Nervous System (330.1, 331.7, 331.89, 331.9, 334.1, 334.2, 335.0, 337.9, 343.0-343.9, 345.6, 348.0, 352.6, 356.0-356.9, 358.0-359.9)
R	Other diseases of the Eye (362.60-362.66, 363.20, 369.00-369.9, 377.16, 378.0-378.9, 379.50-379.59)
S	Hearing Deficiency (389.9)
T	Other Diseases of the Heart and Circulatory System (425.0-425.4, 426.0, 426.10-427.42, 427.81-427.9, 434.0-434.9, 453.0)
U	Other Diseases of the Gastrointestinal System (520.0-520.9, 524.00-524.19, 537.1, 550.00-550.93, 553.00-553.9, 560.2, 560.9, 565.1, 569.2, 569.81)
V	Other Diseases of the Genital and Urinary Systems (593.3, 593.5, 593.82, 596.1, 596.2, 596.9, 599.1, 599.6, 619.0-619.9)
W	Other Fetal/Placental Anomalies (653.7, 658.8)
X	Other Musculoskeletal system Diseases (733.3)
Y	Maternal Exposures Affecting the Fetus (760)

## Appendix C

### MICHIGAN BIRTH DEFECTS REGISTRY REPORT

Vital Records and Health Data Development Section

Michigan Department of Community Health

☐ Correction

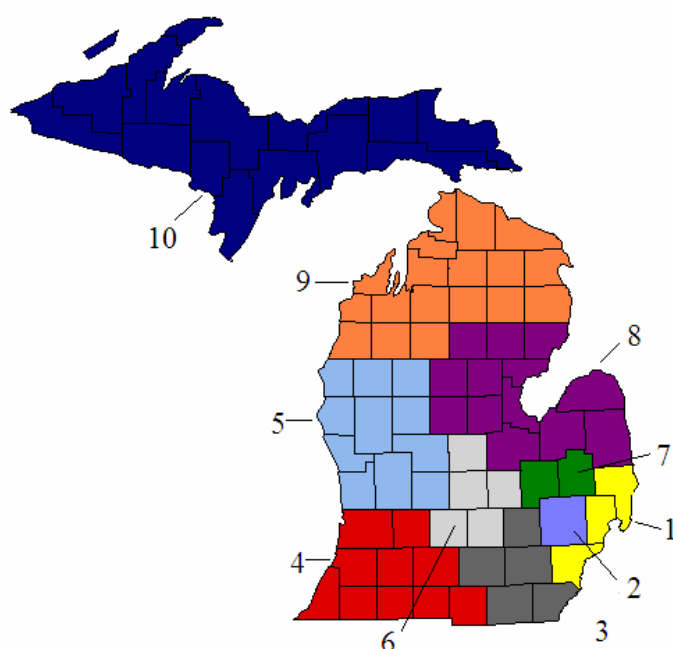
1. Name of Child (Last)		(First)		(Middle Initial)	
2. If the child has been identified by another name (AKA – also known as)					
3. Child's Current Street Address				Apartment No.	P.O. Box No.
City		State		Zip Code	Telephone No.
4. Child's Social Security Number (if known)	5. Medical Record Number		6. Sex		7. Plurality
			<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated		<input type="checkbox"/> Single <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third or More
8. Child's Medicaid # (if known)	9. Date of Birth (Month) (Day) (Year)				
10. Hospital / Place of Birth					
City		State		11. Mother's Social Security Number	
12. Mother's Name (Last)		(First)		(Middle Initial)	
13. Name of Facility Submitting Form		City		State	
14. Patient Status	15. Admission Status	16. Admission Date (Month) (Day) (Year)	17. Discharge Status	18. Discharge Date (Month) (Day) (Year)	19. Birth Status
<input type="checkbox"/> Inpatient <input type="checkbox"/> Outpatient	<input type="checkbox"/> Any Admission <input type="checkbox"/> Transferred		<input type="checkbox"/> Alive <input type="checkbox"/> Transferred <input type="checkbox"/> Dead		<input type="checkbox"/> Live Birth <input type="checkbox"/> Stillborn Birth Weight _____
20. Diagnoses (attach additional forms if more than 5 diagnoses)				ICD-9-CM Code	21. Procedure Codes – ICD-9-CM Codes
1. _____				_____	_____
2. _____				_____	_____
3. _____				_____	_____
4. _____				_____	_____
5. _____				_____	_____
Syndrome _____				_____	_____
22. Cytogenetics					_____
<input type="checkbox"/> Not Stated <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Pending <input type="checkbox"/> No Growth <input type="checkbox"/> Not Done					_____
If Abnormal, Describe _____				ICD-9-CM Code	_____
					_____
23. Name of Laboratory				City	
24. Name of Person Completing Form					
(Last) _____		(First) _____			
Telephone Number _____					



## Appendix D

<b>MICHIGAN BIRTH DEFECTS REGISTRY</b> <b><u>"CYTOGENETICS"</u> REPORT</b>			
<b>1. NAME OF CHILD</b> (Last)                                      (First)                                      (Middle initial)			
<b>2. IF THE CHILD HAS BEEN IDENTIFIED BY ANOTHER NAME (AKA - also known as)</b>			
<b>3. CHILD'S CURRENT STREET ADDRESS</b> _____  <b>CITY</b> _____		<b>APARTMENT No.</b> _____  <b>STATE</b> _____	<b>P.O. BOX No.</b> _____  <b>ZIP CODE</b> _____
<b>4. CHILD'S SOCIAL SECURITY No. (if known)</b>	<b>6. MEDICAL RECORD No.</b>	<b>8. SEX</b>  <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated	<b>10. PLURALITY</b>  <input type="checkbox"/> Single <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third or More
<b>5. CHILD'S MEDICAID No. (If known)</b>	<b>7. DATE OF BIRTH</b> (Month)      (Day)      (Year) _____	<b>9. DECEASED</b>  <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>11. HOSPITAL - PLACE OF BIRTH</b>  _____			
<b>12. MOTHER'S LAST NAME</b>		<b>FIRST NAME</b>	<b>M.I.</b> <b>SOCIAL SECURITY No.</b>  _____
<b>13. HOSPITAL - PLACE OF DIAGNOSIS</b>		<b>CITY</b>	<b>STATE</b>
<b>14. <u>CYTOGENETICS</u>- DESCRIBE FINDINGS</b>		<b>ICD - 9 - CM CODE</b>	
_____ _____ _____		_____ _____ _____	
<b>15. NAME OF LABORATORY</b>		<b>CITY</b>	
<b>16. <u>LAST NAME</u> OF PERSON COMPLETING THIS FORM</b>  (LAST)		<b><u>FIRST NAME</u> OF PERSON COMPLETING THIS FORM</b>  (FIRST)	
<b>TELEPHONE NUMBER</b>		<b>DATE COMPLETED</b>  (Month) _____ (Day) _____ (Year) _____	

## Appendix E



**Figure 1:** Geographic regions approximate pediatric specialty care service areas.

<b>Region 1</b>	<b>Region 5</b>	<b>Region 8</b>	Manistee
Macomb	Ionia	Arenac	Missaukee
Wayne	Kent	Bay	Montmorency
St. Clair	Lake	Clare	Oscoda
	Mason	Gladwin	Otsego
<b>Region 2</b>	Mecosta	Huron	Presque Isle
Oakland	Montcalm	Iosco	Wexford
	Muskegon	Isabella	
<b>Region 3</b>	Newaygo	Midland	<b>Region 10</b>
Jackson	Oceana	Ogemaw	Alger
Lenawee	Osceola	Roscommon	Baraga
Livingston	Ottawa	Saginaw	Chippewa
Monroe		Sanilac	Delta
Washtenaw	<b>Region 6</b>	Tuscola	Dickinson
	Clinton		Gogebic
<b>Region 4</b>	Eaton	<b>Region 9</b>	Houghton
Allegan	Gratiot	Alcona	Iron
Barry	Ingham	Alpena	Keweenaw
Berrien	Shiawassee	Antrim	Luce
Branch		Benzie	Mackinac
Calhoun	<b>Region 7</b>	Cheboygan	Marquette
Cass	Genesee	Charlevoix	Menominee
Hillsdale	Lapeer	Crawford	Ontonagon
Kalamazoo		Emmet	Schoolcraft
St. Joseph		Grand Traverse	
Van Buren		Kalkaska	
		Leelanau	

**Table 1:** Prevalence of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2008.

MBDR (1992-2008)	Live Births	Neural Tube Defect		Orofacial Clefts		Chromosomal Anomalies <sup>3</sup>		Congenital Heart Defects	
		Number	Prevalence <sup>1,2</sup>	Number	Prevalence <sup>1,2</sup>	Number	Prevalence <sup>1,2</sup>	Number	Prevalence <sup>1,2</sup>
State of Michigan	2,249,787	1,444	6.4	3,528	15.7	3,052	13.6	34,132	151.7
Region 1	725,436	413	5.7	989	13.6	955	13.2	12,057	166.2
Region 2	263,812	138	5.2	349	13.2	345	13.1	4,887	185.2
Region 3	186,108	121	6.5	264	14.2	246	13.2	2,985	160.4
Region 4	221,112	156	7.1	391	17.7	288	13.0	2,590	117.1
Region 5	319,819	258	8.1	580	18.1	471	14.7	4,373	136.7
Region 6	122,337	88	7.2	224	18.3	191	15.6	1,299	106.2
Region 7	125,983	76	6.0	196	15.6	156	12.4	1,470	116.7
Region 8	151,573	107	7.1	268	17.7	220	14.5	2,883	190.2
Region 9	79,214	60	7.6	171	21.6	120	15.1	1,108	139.9
Region 10	54,393	27	5.0	92	16.9	59	10.8	478	87.9

<sup>1</sup> Prevalence rates are based on resident occurrences. Data are current through August 2010.

<sup>2</sup> Prevalence rate expressed as cases per 10,000 live births.

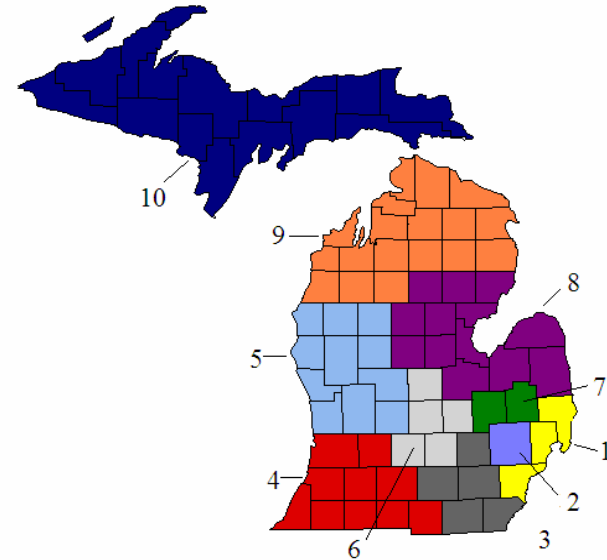
**Table 2:** Infant fatality of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2008.

MBDR (1992-2008)	Neural Tube Defect		Orofacial Clefts		Chromosomal Anomalies <sup>3</sup>		Congenital Heart Defects	
	Deaths	Fatality <sup>1,2</sup>	Deaths	Fatality <sup>1,2</sup>	Deaths	Fatality <sup>1,2</sup>	Deaths	Fatality <sup>1,2</sup>
State of Michigan	342	236.8	224	63.5	588	192.7	2538	74.4
Region 1	83	201.0	73	73.8	193	202.1	853	70.7
Region 2	26	188.4	13	37.2	44	127.5	209	42.8
Region 3	28	231.4	16	60.6	38	154.5	109	36.5
Region 4	48	307.7	21	53.7	61	211.8	256	98.8
Region 5	65	251.9	50	86.2	93	197.5	510	116.6
Region 6	16	181.8	7	31.3	34	178.0	104	80.1
Region 7	23	302.6	10	51.0	34	217.9	149	101.4
Region 8	34	317.8	16	59.7	42	190.9	193	66.9
Region 9	11	183.3	13	76.0	24	200.0	111	100.2
Region 10	8	296.3	5	54.3	14	237.3	44	92.1

<sup>1</sup>Infant fatality rates are based on resident occurrences of cases identified in the first year of life

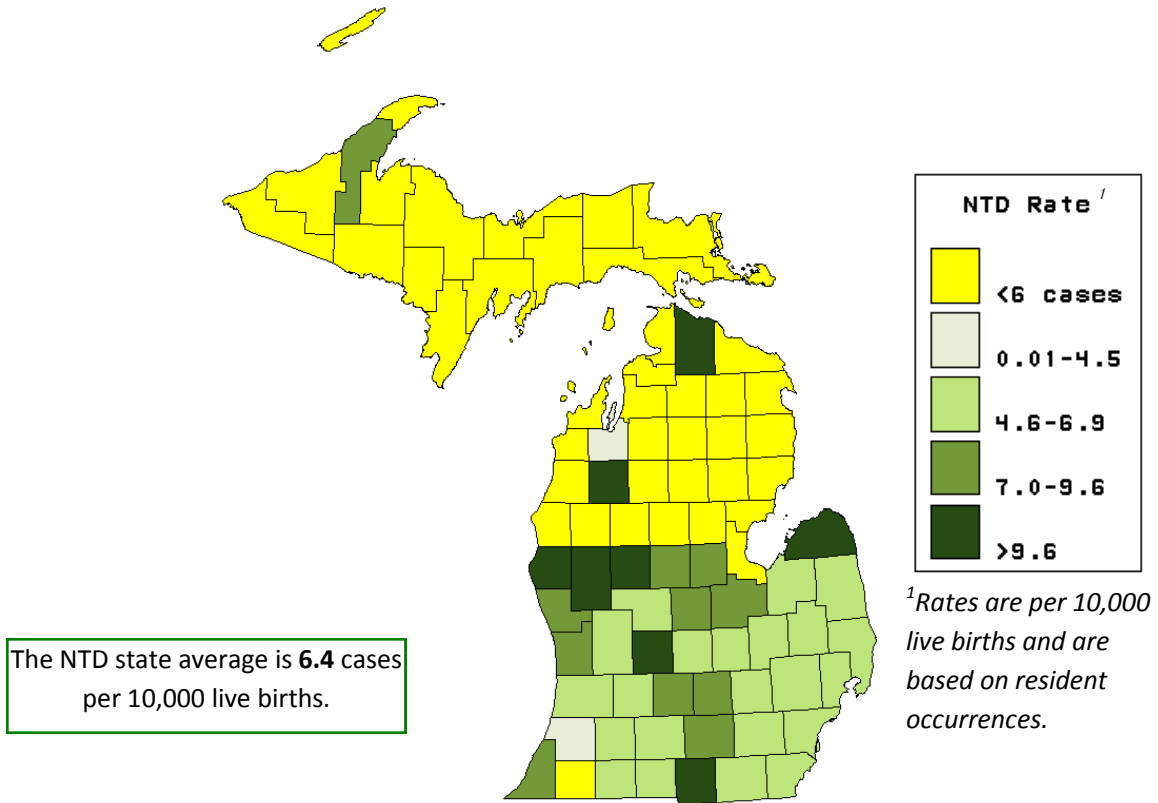
<sup>2</sup>Infant fatality rate expressed as cases per 1,000 cases.

<sup>3</sup>Chromosomal anomalies category includes trisomy 13, trisomy 18, and trisomy 21

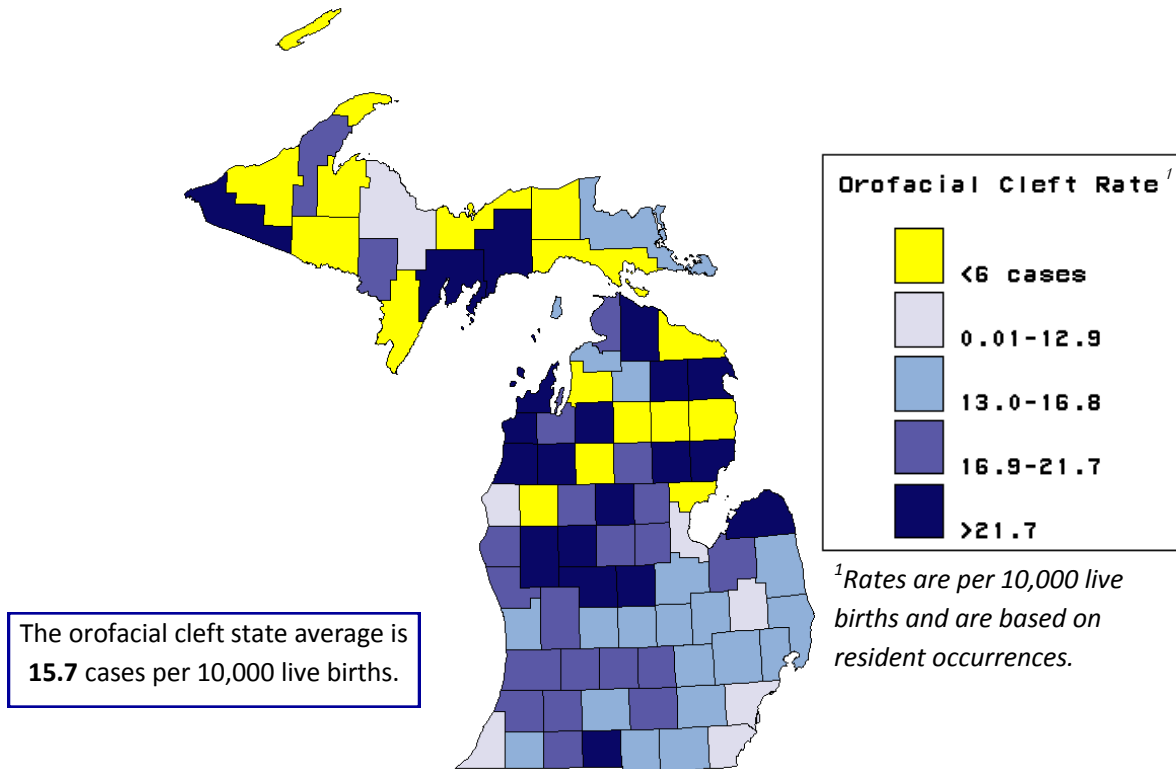


**Figure 2:** Geographic regions approximate pediatric specialty care service areas.

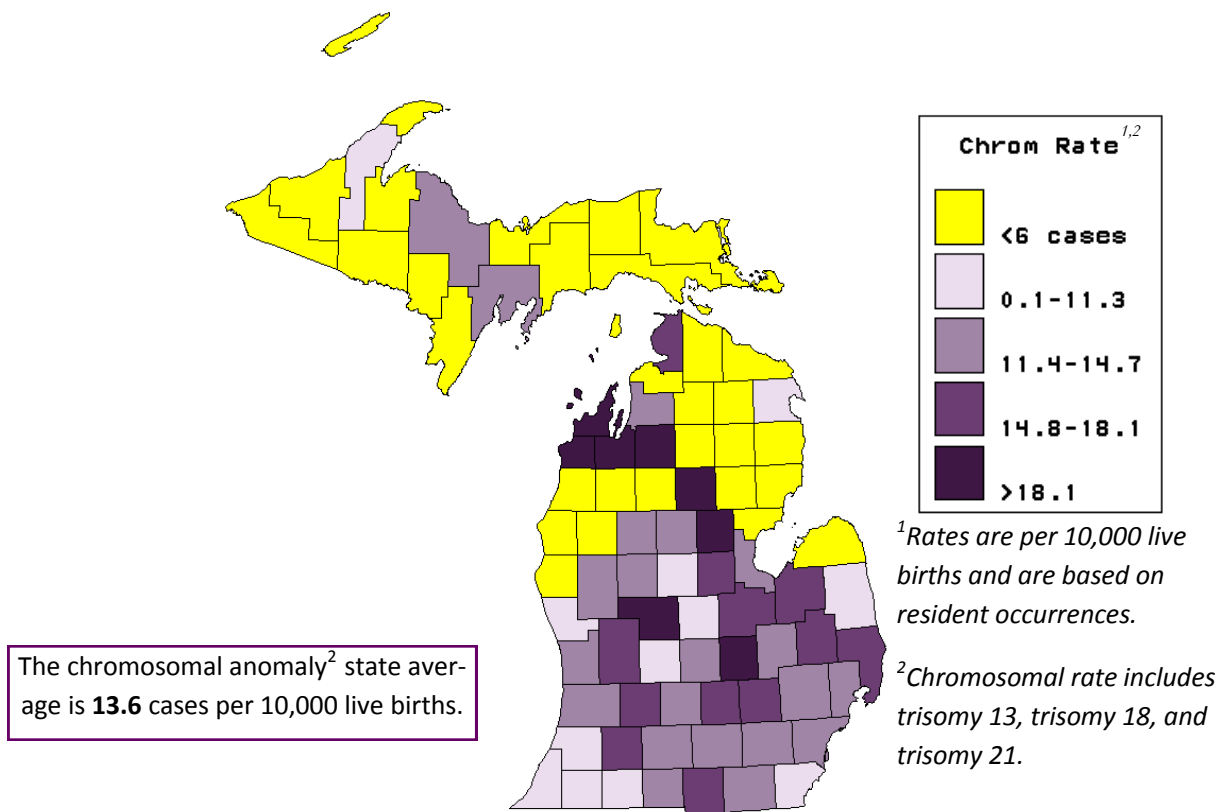
## Appendix F



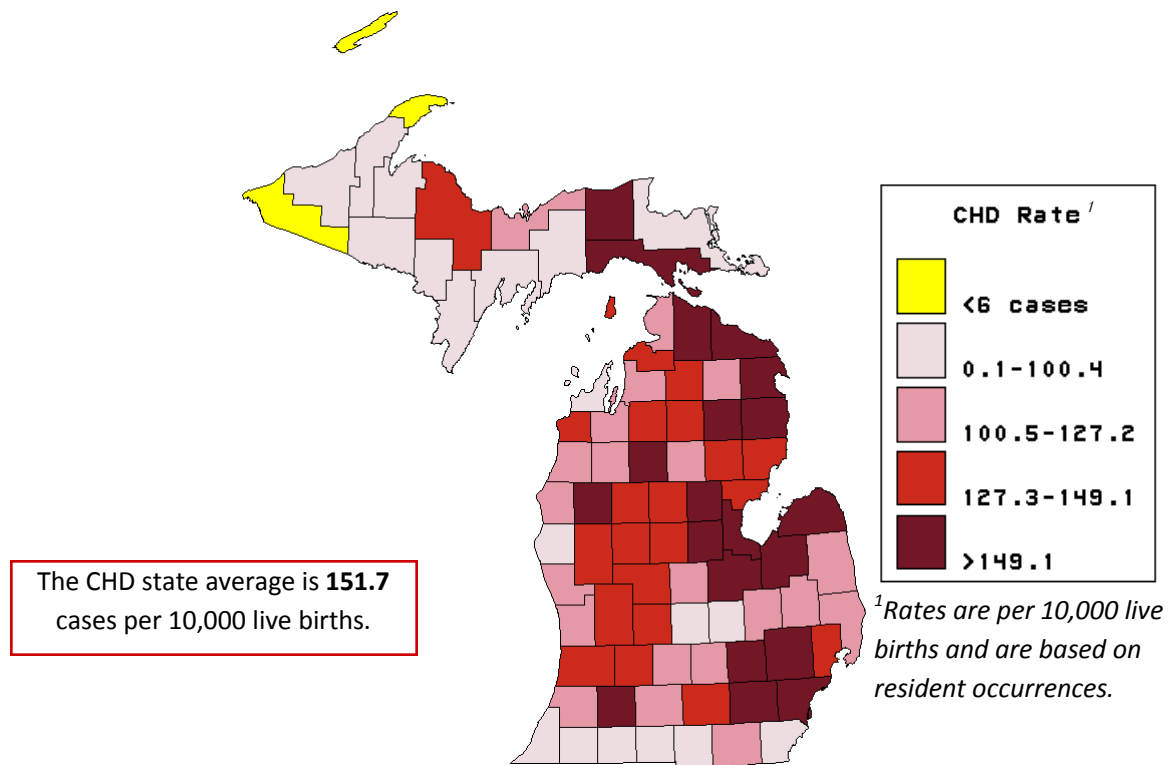
**Figure 1:** Prevalence of neural tube defect (NTDs) by county: MBDR, 1992-2008.



**Figure 2:** Prevalence of orofacial clefts (lip and palate) by county: MBDR, 1992-2008.



**Figure 3:** Prevalence of chromosomal anomalies by county: MBDR, 1992-2008.



**Figure 4:** Prevalence of congenital heart defects (CHD) by county: MBDR, 1992-2008.

information.