

# The Michigan Monitor

Following trends, promoting prevention  
and linking families to resources

Winter 2013

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## Michigan Birth Defects Registry (MBDR)

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. Rules governing the MBDR specify the conditions and approval processes under which this information may be released.

### MBDR Goals:

- 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.



## Birth Defects Reporting

Did you know that the Michigan Birth Defects Registry uses a passive system of reporting? That means that we rely on staff at hospitals, laboratories, and clinics to report conditions to the registry. In the years 2009 and 2010, there were 7,428 and 7,168 cases of birth defects reported for children under one year of age, respectively. The rate for either year was about 660 cases per 10,000 resident live births. Many thanks to those dedicated people doing the work of helping us identify the prevalence of birth defects in Michigan.

## Reporting Methods

Methods of reporting cases are selected based on the needs of the reporting facility. Reporting methods include:

- Paper Abstract: This method uses a standardized print form 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. Data from three sources (reports, births and deaths) are used to develop a complete record on each case.

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

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

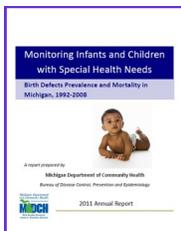
## Points of Interest

- ♥ *Congenital heart defects are the most common cause of birth-defect related infant deaths in the U. S.*
- ♥ *Seven congenital heart defects are considered "critical", as they are life-threatening and require urgent intervention*
- ♥ *February 7th–14th, 2013 is Congenital Heart Defect Awareness Week*

## Online Training Course Available for Birth Defect Reporting

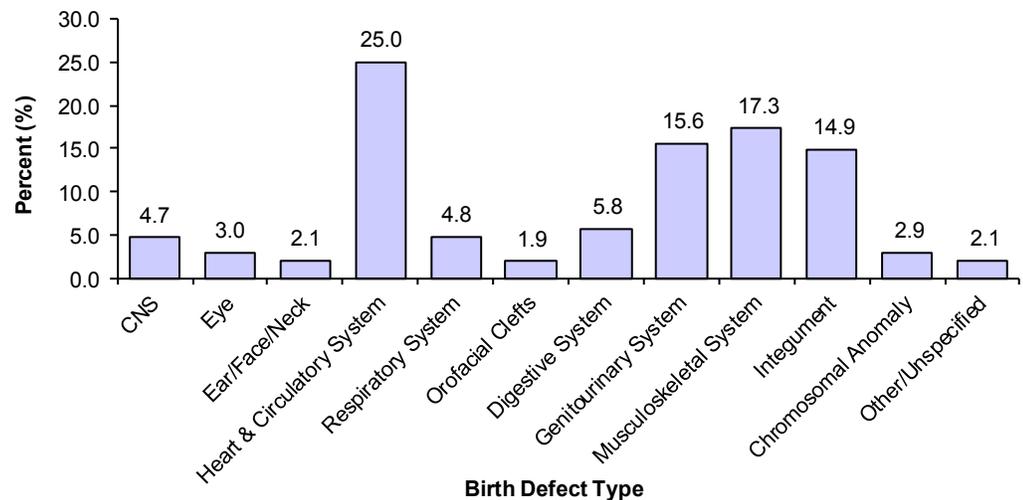
The Birth Defects Registry offers a free, online training course hosted by MPHI which highlights the value of the MBDR and teaches individuals how to complete most recent paper-based and electronic reporting forms. A link to this training module can be found at: <http://training.mihealth.org/coursedetail.htm>. New users will need to register and create an account at the MPHI learning site. Returning users may review the course for updating information and skills as desired.

The chart (right) shows the prevalence of birth defects by category in Michigan. For more information about birth defects surveillance activities and statistics, please see our 2011 Surveillance Report.



[http://www.michigan.gov/documents/mdch/Birth\\_Defect\\_Annual\\_Report\\_352411\\_7.pdf](http://www.michigan.gov/documents/mdch/Birth_Defect_Annual_Report_352411_7.pdf)

**Figure 1: Distribution of birth defect categories in Michigan, MBDR 2008**



## Congenital Heart Defects in Michigan Newborns

Congenital heart defects (CHD) are the most common congenital anomaly. There are many types of CHDs, ranging from minor conditions that may go undiagnosed for many years to those that may cause death soon after birth. CHDs are the most common cause of birth-defect related infant deaths in the U.S. Critical congenital heart defects (CCHD) are a subgroup of CHD which require urgent intervention. CCHDs may be detected soon after birth with pulse oximetry.

### Pulse Oximetry Screening for CCHD

In 2011, pulse oximetry was recommended by the Health and Human Services Secretary's Advisory Committee for Heritable Disorders in Newborn and Children (SACHDNC) as an important screening tool for detection of CCHD in asymptomatic newborns. The Michigan Department of Community Health (MDCH) is conducting a demonstration program to assess the feasibility of screening all Michigan newborns for CCHD using pulse oximetry prior to hospital discharge. Although not currently mandated in Michigan, pulse oximetry screening of newborns has already been implemented as a standard practice in many Michigan hospitals.

### Critical Congenital Heart Disease Newborn Screening Demonstration Program



<http://www.michigan.gov/cchd>

Michigan's CCHD Advisory Committee was established in March 2012 to provide ongoing clinical guidance and expertise in development of screening and follow-up protocols for CCHD in Michigan. The committee consists of physicians, nurses, advocacy organizations and parent representatives from across Michigan.

This screening project is administered through a partnership between the newborn screening (NBS) and birth defects (MBDR) programs and provides a unique opportunity for early detection and follow up of these life threatening conditions.

## Orofacial Clefts in Michigan

Orofacial clefts (OFCs) are made up of two groups: cleft lip with or without (+/-) cleft palate and cleft palate alone. Of the nearly 100,000 birth defects reported in Michigan children up to two years of age between 2001 and 2010, nearly 2,000 were orofacial clefts<sup>2</sup>. Early detection and intervention are critical components in maximizing the outcome of care provided to all children with birth defects. Children with orofacial clefts are at particular risk for developing secondary morbidities if timely and continuous treatment is not received<sup>3</sup>. Secondary health problems including poor nutrition, infections, speech and hearing difficulties, dental, learning, social, and emotional problems contribute to the large economic and psychosocial burden on children with OFCs and their families.

In general, babies are born with cleft lip +/- cleft palate more frequently than babies born with cleft palate alone. In an embryo, the lip develops before the palate and these processes are determined by separate pathways. Cleft lip +/- cleft palate and cleft palate alone may either be isolated, meaning the only birth defect a newborn has, or syndromic, meaning it is part of a group of birth anomalies with a common cause. Clefing can be unilateral (on one side only) or bilateral (on both sides).

In Michigan, the rate of births with orofacial clefts remains relatively stable at about 16 cases per 10,000 live births. Younger mothers (< 24 years) and those with pre-term deliveries (< 37 weeks) tend to have more babies with orofacial clefts. The prevalence rate of orofacial clefts in whites is higher than in blacks. For a more detailed breakdown of Michigan births with orofacial clefts, see the MDCH 2011 Surveillance Report, "Monitoring Infants and Children with Special Needs".



**Figure 2:** Cleft Lip (Top) and Cleft Palate (Bottom).<sup>9</sup>

## MBDR Follow Up Survey of Parents of Children with Oral Clefts

The Michigan Birth Defects Follow Up Program is conducting a study entitled, **A Needs Assessment Survey for Parents of Children with Oral Clefts in Michigan**. The purpose of this study is to find out about the experiences of parents of children with oral clefts. The survey was developed with the input of healthcare providers and parents who have children with oral clefts. Parents with children reported to the registry during the years 2009-2011 with an orofacial cleft will be invited to participate. Our goal is to find out if there are gaps in the information, services, and support that exist, and if so, how they may be addressed.

### Introducing New MBDR Team Members

#### **Sarah Lyon-Callo**

Sarah is the new director of our Lifecourse Epidemiology and Genomics Division (LEGenD). Newborn Screening and Birth Defects Programs are within LGenD. Sarah returns to us from epidemiologic study at the University of Michigan School of Public Health.

#### **Evelyn Quarshie**

Evelyn is our new epidemiologist, a position that is shared with the EHDI Program. Evelyn comes to us from Columbus, Ohio where she also worked in public health, in the areas of obesity, nutrition, physical activity and tobacco use prevention.

#### **Mary Mobley**

Mary is our new cardiovascular genomics and birth defects consultant. In addition to working with birth defects, a portion of her time is spent with the sudden cardiac death of the young (SCDY) program. Mary's background is in education and recent training as a genetic counselor.

## Following trends, promoting prevention and linking families to resources

For more information or to receive future editions, please contact:  
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## More Program Updates

### ICD-10-CM

The deadline for converting to the newest ICD –CM (International Classification of Diseases, Clinical Modification) code has been pushed back to October 1<sup>st</sup>, 2014. We will be working to add all of the ICD-10-CM codes to the Web EBC system over the next few weeks. Birth registry staff will see the new codes appearing in the drop-down menu while reporting a birth defect in EBC. Although the new codes will appear in the menu, there is no need to begin using these until the deadline date. Please continue to use the ICD-9-CM codes that appear in the menu until that time.



You can find the Michigan Monitor online at  
[www.michigan.gov/mchepi](http://www.michigan.gov/mchepi)

For more information about MBDR data and statistics:  
[http://www.michigan.gov/mdch/0,1607,7-132-2944\\_4670---,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2944_4670---,00.html)

## Michigan Health Information Network (MiHIN)

In an effort to improve health care quality, cost, and patient safety, Michigan is developing a framework through which electronic health information may be accessed and exchanged by healthcare providers. The MiHIN is a joint effort among the Michigan Department of Community Health (MDCH), Department of Management, Technology, and Budget (DTMB) and a broad group of stakeholders across the state. Health care providers will be able to access and exchange electronic health information when they need it most, at the point of care, and regardless of provider technology choices.

## References

1. Dastgiri S, Gilmour WH, Stone DH. Survival of children born with congenital anomalies. *Arch Dis Child*. 2003; 88: 391-394
2. Michigan Department of Community Health. Birth Defects Registry (BDR) Preliminary Summary Report, June, 2012.
3. Wehby, G., & Cassell, C. H. (2010). The Impact of Orofacial Clefts on Quality of Life and Health Care Use and Costs. *Oral Dis*. 16 (1), 3-10.

Michigan Department  
of Community Health



Rick Snyder, Governor  
James K. Haveman, Director

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Early Hearing Detection and Intervention (EHDI)  
Fetal Alcohol Spectrum Disorders (FASD)  
Fetal and Infant Mortality Review (FIMR)  
Michigan Birth Defects Registry (MBDR)  
MI Healthy Baby  
Newborn Screening (NBS)  
Special Supplemental Nutrition Program for  
Women, Infants, and Children (WIC)

### Michigan Birth Defects Follow Up Program

#### Contact Information:

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

Website: [www.michigan.gov/genomics](http://www.michigan.gov/genomics)