# Birth Defects

# The Michigan Monitor

Summer 2011 Volume 5 Issue 2 Following trends, promoting prevention and linking families to resources

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#### **Points of Interest**

- Children with birth defects make up 50 percent of all deaths in those age one to two years old.
- Children with birth defects are at greater risk of death due to causes other than a birth defect.
- \* The disparity in mortality among black and white infants with birth defects has decreased over the years.

# **Infant and Child Mortality**

Infant mortality is associated with a variety of factors such as quality and access to prenatal care, maternal health, socioeconomic conditions, and public health practices.1 Nationally, infant mortality declined from about 100 deaths per 1,000 live births in 1900 to about 7 deaths per 1,000 live births in 2000.1 Infant mortality is more common among those born preterm or born with a congenital anomaly. In 2006, the child



mortality rate for those up to 19 years of age was about 65 deaths per 100,000.2 Mortality among children with a birth defect is higher than for the overall population. In Michigan, children with birth defects make up about 50 percent of the deaths in those age one to two years old.3 This issue of the Michigan Monitor focuses on infant and childhood mortality and assesses the underlying cause of death among those with a birth defect.

# **Birth Defects and Mortality**

Both the overall infant mortality rate and the mortality rate among those with birth defects decreased over the years. In Michigan, the mortality rate among infants with a birth defect decreased from about 43 deaths per 1,000 cases of birth defects in 1996 to about 35 deaths per 1,000 cases in 2008. The decrease in birth defect mortality may in part be due to advances in medical care and improvements in surgical repairs of defects.4 In Michigan, the mortality rate among all children up to seventeen years of age is about 10 deaths per 1,000 live births, while among children with birth defects, the rate is about 60 deaths per 1,000 infants with defects.3 Figure 1 shows the percent of all deaths that occur in children with a birth defect, by age of death. Almost half of all deaths among those age one to two years are in children with a birth defect. Considering deaths in children

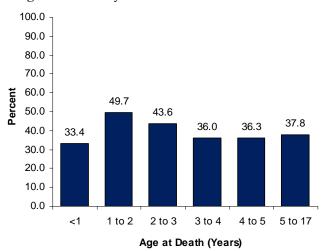


Figure 1: Percent of all deaths among children with a birth defect, by age at death: MBDR, 1992-2008.3

age five to seventeen years, about 40 percent of all deaths were among children with birth defects. Deaths in those less than one year of age are more likely to be due to the birth defect itself or additional conditions occurring in the perinatal period, such as prematurity, low birth weight, or birth trauma. Mortality among older children may be due to the birth defect itself but could also be due to other factors such as accidents, injury, or infections. More specific causes of death are reviewed in this issue of the Michigan Monitor.

# **Mortality Among Children with Birth Defects**

#### **Underlying Cause of Death**

Mortality among children with birth defects can be due to many different factors. Insight on causes of mortality comes from death certificate data, which is linked to the Michigan Birth Defects Registry (MBDR). A single underlying cause of death, as determined by the physician, is reported on the death certificate, along with other contributing causes. In this section, we assess the reported underlying cause of death among those with birth defects. Figure 2 shows the percent of deaths that are due to perinatal period conditions and birth defects, by age at death for those with a central nervous system (CNS), heart, digestive, or musculoskeletal defect. Of note, children could have more than one defect and may therefore fall into more than one category. In those who died before one year of age, about 65 percent of deaths were due to birth defects and about 15 percent were due to conditions occurring during the perinatal period (such as prematurity, low birth weight, or maternal factors). In older children, about 35 percent of deaths were due to birth defects and about 5 percent were due to conditions during the perinatal period. Other causes of death can be found in Table 1 and Figure 4.

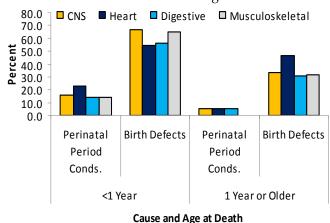


Figure 2: Percent of deaths due to perinatal period conditions and birth defects, by age at death: MBDR, 1992-2008.<sup>3</sup>

#### **Mortality by Race**

Infant mortality among blacks with birth defects is higher than the rate in white infants, but the disparity has declined by about 61 percent in Michigan from 1996 to 2008.<sup>3</sup> The cause for differences in mortality among races is unknown, but may be due to access to care, sociodemographic factors, prematurity, low birth weight, or other factors.<sup>5,6</sup>

Table 1 shows mortality rates (per 1,000 cases) among children with birth defects by underlying cause of death and by age and race. Overall for those who died before one year of age, there were about 31 deaths per 1,000 cases in whites and about 38 deaths per 1,000 cases in blacks. For those who died after one year of age, there were about 9 deaths per 1,000 cases in whites and about 12 deaths per 1,000 cases in blacks.

**Table 1:** Mortality rates among children with birth defects by underlying cause of death: MBDR, 1992-2008.<sup>3</sup>

Underlying	Age at Death < 1		Age at Death >1	
Cause of Death	White	Black	White	Black
Blood / Circulatory	1.5	1.8	0.8	1.5
Perinatal Period Conditions	6.6	11.3	0.3	0.5
Birth Defects	16.0	14.0	2.0	2.1
Digestive / Nutritional	1.2	1.8	0.8	0.5
Accidents / Injury	0.6	1.1	0.9	1.8
Nervous System	0.8	0.7	1.5	2.4
Respiratory	0.7	1.9	0.5	1.2
Infectious Disease	0.7	1.3	0.3	0.5
Cancers	0.2	< 6 cases	0.7	0.6
Other	1.1	2.7	0.2	0.5
Total	30.7	38.4	8.5	12.3

<sup>\*</sup>Mortality rates are per 1,000 cases.

#### **Childhood Deaths**

While most infant deaths in those with birth defects are due to birth defects or conditions occurring during the perinatal period, there are different causes of deaths to those who die after one year of age. Figure 4 shows the percent of deaths in children older than one year by underlying cause among those with CNS, heart, digestive and musculoskeletal defects. Besides the birth defect itself (as seen in Figure 2), nervous system problems are a leading cause of death in these categories. For those with a heart defect, another 10 percent of deaths were due to blood and circulatory problems. For those with a musculoskeletal defect, about 11 percent of deaths were due to respiratory problems or accidents and injury, respectively. Previous research with MBDR data has shown that children with birth defects are about two times more likely to die from accidents and about four times more likely to die from homicides, compared to children without birth defects. Table 2 shows the leading cause of death within causal categories among individuals with birth defects. For example, "hereditary and degenerative disorders" is the leading specific cause of death among those reported to have a nervous system problem as the underlying cause of death.

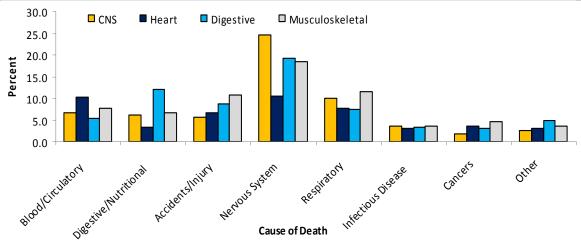


Figure 4: Underlying cause of death in those with a birth defect, who died after one year of age: MBDR, 1992-2008.3

# **Public Health Implications**

To help address birth defects as a cause of infant mortality, the Healthy People 2020 goal for infant mortality due to birth defects is 1.3 deaths per 1,000 live births, a 10 percent improvement from 2006. Reducing overall infant mortality in Michigan is also one of Governor Snyder's top priorities, as seen in the *Michigan Dashboard*, measuring Michigan's success with selected performance indicators (http://www.michigan.gov/midashboard/). Children with birth defects are not only at risk of death due to the birth defect itself, but they also have increased mortality rates across *all* major causes of death, compared to those without defects.<sup>7</sup> The underlying cause of death among those with birth defects, especially in older children, needs to be assessed to identify prevention strategies aimed at lowering childhood mortality. Local Fetal and Infant Mortality Review (FIMR) and Child Death Review (CDR) Teams in Michigan help to identify risk factors and contributors to these deaths and work to improve systems of care to protect vulnerable children.

The high mortality rate associated with birth defects underscores the need for family support. State programs help families meet the special medical, emotional and nutritional needs of children at risk. Respite services protect caregivers' emotional reserves. Hospice and palliative care programs provide pain management, support, and spiritual care, enhancing the quality of life for children with life-limiting conditions and their families.

**Information and Resources** 

- Find out about the **Michigan FIMR** and **CDR** initiatives at: http://michigan.gov/mdch/0,1607,7-132-2942\_4911-12563--,00.html (FIMR) and http://www.keepingkidsalive.org/ (CDR). See also the **National Center for the Review and Prevention of Child Deaths** at www.ChildDeathReview.org.
- The MDCH Children's Special Health Care Services (CSHCS) program (www.michigan.gov/cshcs) is for children and some adults with special health care needs and their families. The Family-to-Family Health Information Center (F2FHIEC) is a portal to more Michigan resources. Go to www.bridges4kids/f2f/.
- The Special Supplemental Nutrition Program for Women Infants and Children, WIC (www.michigan.gov/wic/) helps with special formulas for certain medical conditions and general food needs.

**Table 2:** Leading causes of death in each category: MBDR Data, 1992-2008.<sup>3</sup>

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Category	Leading Cause	
Blood /	Cerebrovascular disease,	
Circulatory	pulmonary circulation	
Perinatal Period Conditions	Respiratory and cardiovascular disorders, length of gestation and fetal growth	
Birth Defects	Heart, respiratory, CNS	
Digestive /	Diseases of intestines and	
Nutritional	peritoneum	
Accidents / Injury	Threats to breathing, wounds	
Nervous	Hereditary and degenerative	
System	diseases	
Respiratory	Pneumonia and influenza	
Infectious Disease	Bacterial diseases	
Cancers	Leukemia	
Other	Ill-defined conditions	

- 2-1-1 is a telephone number that connects people in many
  Michigan communities with important services, supported by
  United Way of America and the Alliance of Information and
  Referral Systems (AIRS). Connect online at www.umich.org/2-1-1.
- The Child Welfare Information Gateway (www.ChildWelfare.gov) is a national portal to comprehensive information and resources to help protect children and strengthen families. Find current National Abuse and Neglect Data Systems (NCANDS) statistics in the Child Maltreatment 2009 report.
- National Hospice and Palliative Care Organization (NHPCO) provides information and resources. Visit www.nhpco.org to find out more. Information and support for caregivers is the focus of Caring Connections, go to www.caringinfo.org.

# Following trends, promoting prevention and linking families to resources

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### **Program Updates**

#### **ICD-10-CM Update**

Beginning in August 2011, all reportable conditions currently listed in the Web Electronic Birth Certificate (EBC) portion for reporting birth defects will have ICD-10-CM codes added to the drop down menu for reportable conditions. This addition to the EBC menu will allow facilities to report birth defects using the

ICD-10-CM codes as soon as the new system for coding and billing is implemented in their facility. The ICD-9-CM codes will remain in the same drop down menu so that they can be assigned for reporting as long as necessary.



# Acknowledgments

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#### References

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