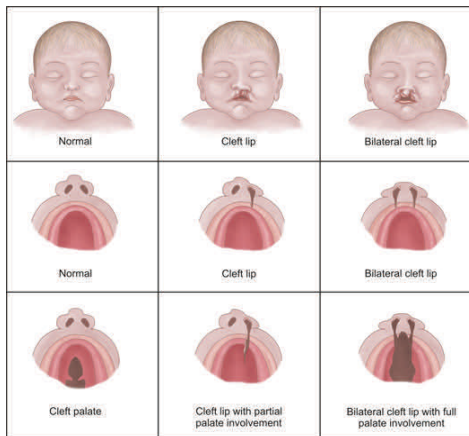


## Facts about Cleft Lip (CL) with and without Cleft Palate (CP) 2000-2010, Arizona

### Definition and Types

Cleft Lip (CL) is a type of birth defect that occurs when the lip does not fully close within the first four to seven weeks of conception. The severity of the lip opening can be as minimal as notch in the lip or a large gap from the top of the lip to the bottom of the nose. The split in the lip can be on one or both sides of the lip. Surgery within the first 12 months of birth can correct CL.<sup>1</sup> Cleft lip can occur alone, or with cleft palate.



Clinical presentation of CL/CP<sup>2</sup>

Children with CL may have a variety of health problems. Some children may need assistance with breathing, eating, and talking. Ear infections, loss of hearing, and dental problems are common in children with CL. Problems with adjusting to social situations may influence how the child learns and behaves.<sup>3</sup>

### United States Estimates

There are approximately 4,200 babies in the U.S. are born with CL/CP each year.<sup>1</sup> The societal and economic lifetime cost associated with caring for a child that has been diagnosed with CL/CP is at least \$100,000.<sup>3</sup>

### United States Estimates (cont'd.)

In 1992, the Centers for Disease Control and Prevention (CDC) recommended that women of childbearing age consume 400 micrograms of synthetic folic acid daily. Then in 1997-1998, the Food and Drug Administration required the addition of folate to enriched cereal-grain products.<sup>5</sup> The U.S. prevalence rate for CL/CP between 1999 and 2000 was 9.0 cases per 10,000 live births. Fortification was associated with a 5% drop in CL/CP rates in the U.S.<sup>6</sup>

### ABDMP Data Collection

The ABDMP staff reviews hospital reports, and birth and death certificates in order to identify potential cases. If potential cases are identified, the staff review the medical records to confirm that the child has a reportable birth defect. Once confirmed, information from the abstract is entered into the Arizona Birth Defects Monitoring Program.<sup>4</sup>

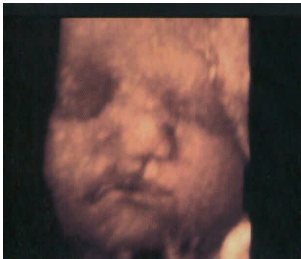
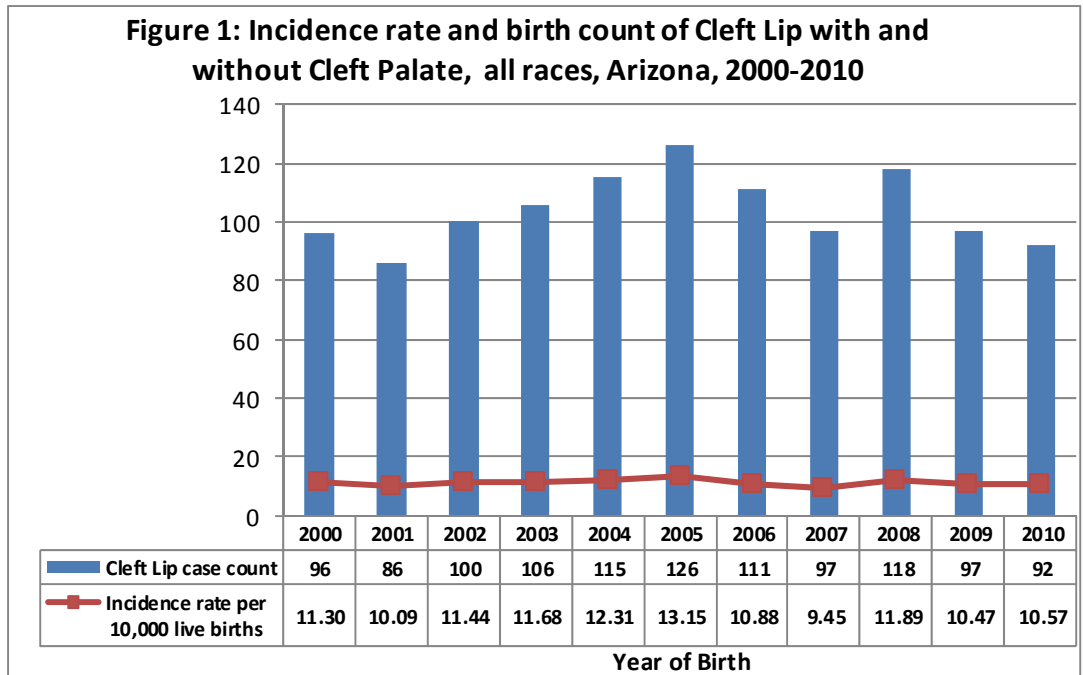
### Cleft Lip/Cleft Palate in Arizona

Approximately 105 babies are born each year in Arizona with CL with and without CP.<sup>7</sup> Between January 2000 and December 2009, the average rate of CL in Arizona remained relatively constant—averaging around 11.26 per 10,000 live births (range 10.09-13.15)

The rate for Whites (non-Hispanic) was 10.36 per 10,000 live births. The rate for Native Americans was 23.3 per 10,000 live births, an elevated rate compared to Whites (non-Hispanic). The rate for Hispanics was 10.10 per 10,000 live births. Blacks and Asians had lower rates than both Whites and Hispanics, with rates of 5.77 and 9.73 per 10,000 live births respectively.

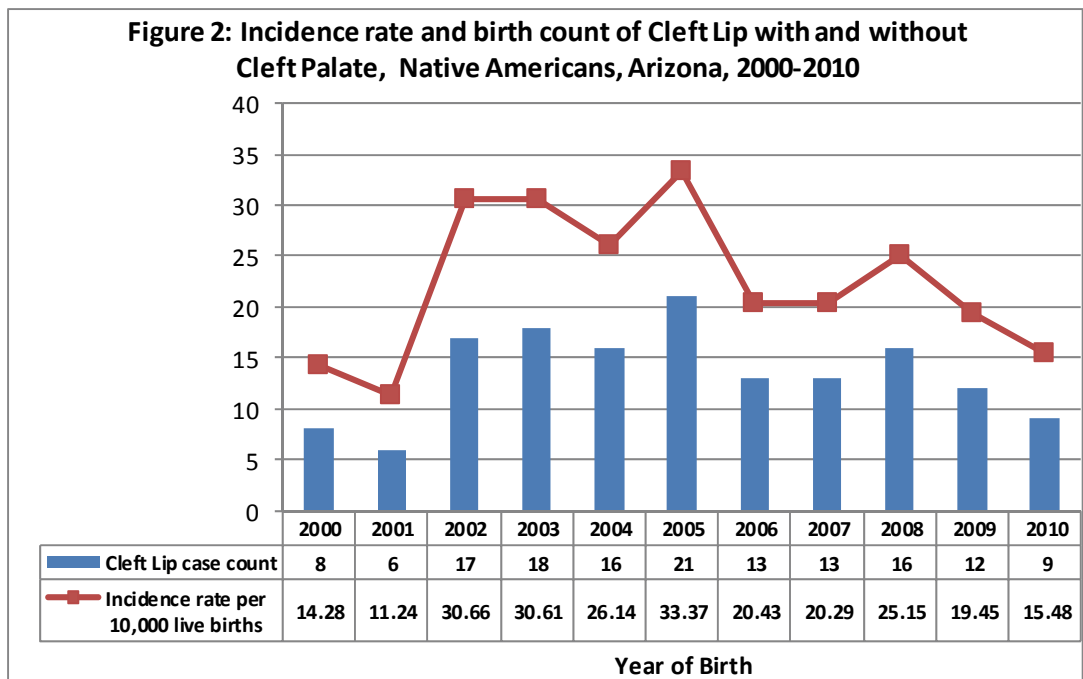
## Cleft Lip in Arizona

Figure 1: The average rate of cleft lip with and without cleft palate for all races in Arizona between 2000 and 2010 is 11.20 cases per 10,000 live births.



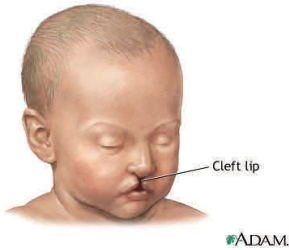
A 3D clinical presentation of CL.<sup>8</sup>

Figure 2: The average rate of cleft lip with and without cleft palate in the Native American population between 2000 and 2010 is 22.46 per 10,000 live births.



## Facts about Cleft Lip (CL) with and without Cleft Palate (CP) 2000-2010, Arizona

Figure 3: The average rate of cleft lip with and without cleft pPalate in the Hispanic population between 2000 and 2010 is 10.35 per 10,000 live births.



Baby with CL<sup>9</sup>

Figure 3: Incidence rate and birth count of Cleft Lip with and without Cleft Palate, Hispanics, Arizona, 2000-2010

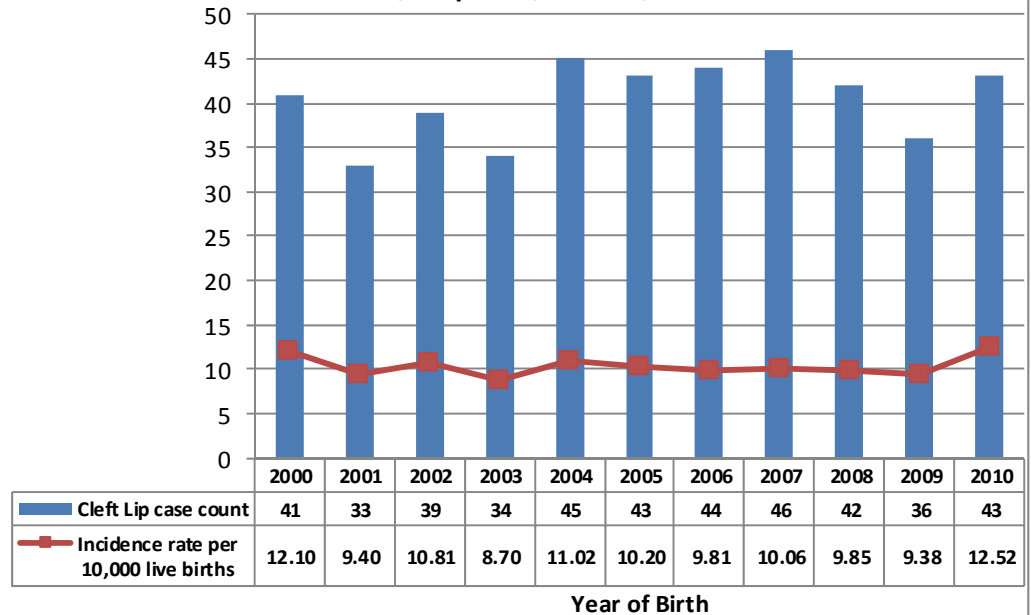
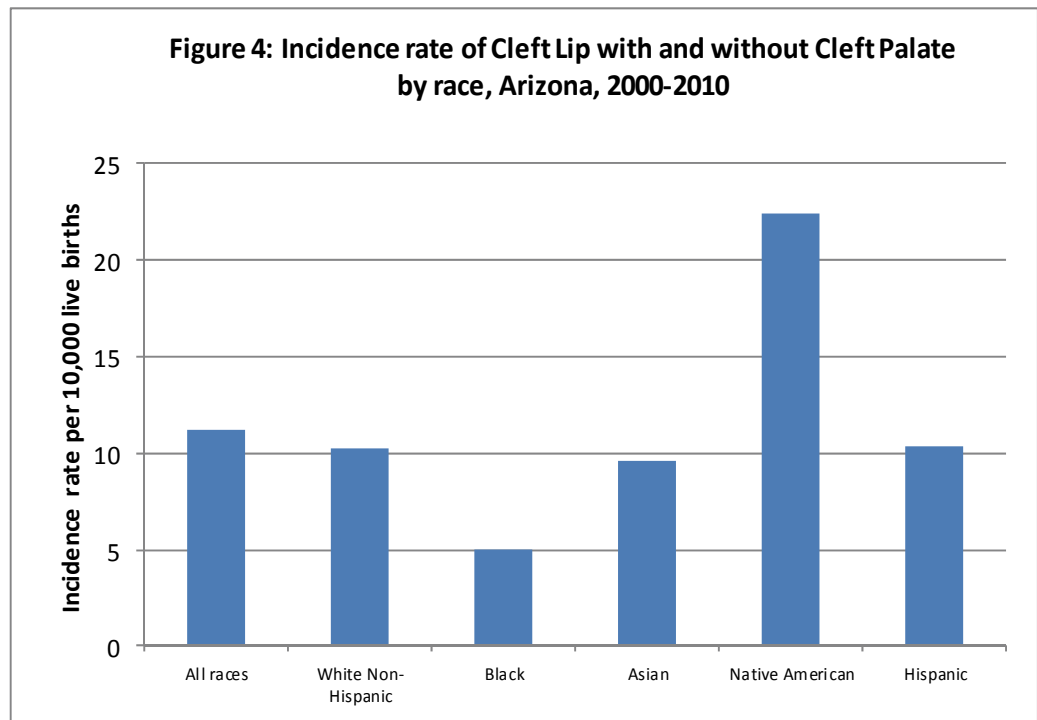


Figure 4: The average rate of cleft lip with and without cleft palate by race/ethnicity for births between 2000 and 2010.



Types of CL<sup>10</sup>

Figure 4: Incidence rate of Cleft Lip with and without Cleft Palate by race, Arizona, 2000-2010



## Prevention

Research has demonstrated that smoking may be a direct cause of CL and CP, and that alcohol consumption is associated with the development of CL/CP. Therefore, women who are planning a pregnancy should not drink alcohol or smoke tobacco.<sup>11,12</sup> Also, some studies suggest folic acid consumption around the time of conception may reduce CL/CP.<sup>13</sup>

## Referral Services

The ABDMP identifies children with birth defects so that they can be referred to outreach services.

- The Arizona Early Intervention Program (AzEIP) is a state-mandated outreach program that provides medical services for children up to three years of age. Some benefits of this program include counseling, physical therapy, and developmental screening. Utilizing this service enables children and families to gain the support they need.<sup>15</sup>
- A second state mandated resource is Children's Rehabilitative Services (CRS). This program involves specialty physicians that assist in the treatment of chronic conditions associated with birth defects.<sup>16</sup>
- The March of Dimes (MOD) is a nonprofit agency that promotes the health of babies by preventing birth defects, prematurity, and infant deaths.<sup>17</sup>

## ABDMP Goals

The Arizona Birth Defects Monitoring Program (ABDMP) is a statewide, population-based, active surveillance program that collects and analyzes information on children with reportable birth defects diagnosed within the first year of life.

### The goals of the ABDMP include :

- To reduce the incidence of birth defects in Arizona from preventable causes.
- To produce accurate statistics regarding the occurrence of birth defects in Arizona.
- To identify, report, and investigate various birth defects trends, high-risk populations, and high-risk locations.
- To provide a resource for information about the incidence and epidemiology of birth defects for researchers, health professionals, hospitals, local health agencies, and others with a valid scientific or public health interest.<sup>19</sup>



#ADAM

**Surgery is an important component to treating children with CL.<sup>14</sup>**



**Dietary folate and folic acid can reduce CL/CP.<sup>18</sup>**

We are on the web!

<http://www.azdhs.gov/phs/phstats/bdr/index.htm>

## References

1. March of Dimes Foundation. (2009). Cleft lip and cleft palate. Retrieved March 16, 2009, from [http://www.marchofdimes.com/pnhec/4439\\_1210.asp](http://www.marchofdimes.com/pnhec/4439_1210.asp)
2. Children's Hospital and Health System. (2009). Cleft lip and/or palate. Retrieved March 16, 2009, from <http://www.chw.org/display/PPF/DocID/35472/Nav/1/router.asp>
3. Centers for Disease Control and Prevention. (2004, October 4). Division of oral health: Oral health and quality of life. Retrieved March 16, 2009, from [http://www.cdc.gov/oralhealth/publications/factsheets/sgr2000\\_fs5.htm](http://www.cdc.gov/oralhealth/publications/factsheets/sgr2000_fs5.htm)
4. Arizona Department of Health Services. (2006). 1998-2000 arizona birth defects monitoring program report. Retrieved March 16, 2009, from <http://www.azdhs.gov/phs/phstats/bdr/reports/2007-06-15--1998-2000ABDMPReport-ForPrint.pdf>
5. Canfield, M. A., Honein, M. A., Yuskiv, N., Xing, J., Mai, C. T., Collins, J. S., et al. (2006). National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. Birth Defects Research Part A: Clinical and Molecular Teratology, 76(11), 747-747.
6. Canfield, M. A., Collins, J. S., Botto, L. D., Williams, L. J., Mai, C. T., Kirby, R. S., et al. (2005). Changes in the birth prevalence of selected birth defects after grain fortification with folic acid in the United States: findings from a multi-state population-based study. Birth Defects Res A Clin Mol Teratol., 73(10), 679-689.
7. Cleft lip with and without cleft palate (BPA Codes 749.10-749.29)
8. Setia Manggala Abadi. (2009, February 18). Galery foto. Retrieved March 16, 2009, from <http://www.setiamanggalaabadi.com/galery1/017.jpg>
9. University of Wisconsin Hospitals and Clinics Authority. (2009). Health information: Cleft lip repair. Retrieved March 16, 2009, from <http://apps.uwhealth.org/health/adam/sp/13/100010.htm>
10. Lucina Foundation. (2006). Birth defects: Cleft lip. Retrieved March 16, 2009, from <http://www.lucinafoundation.org/birthdefects-cleftlip.html>
11. MacLehose, R. F., Olshan, A. F., Herring, A. H., Honein, M. A., Shaw, G. M., Romitti, P. A., et al. (2009). Bayesian methods for correcting misclassification: An example from birth defects epidemiology. Epidemiology, 20(1), 27-35.
12. DeRoo, L. A., Wilcox, A. J., Drevon, C. A., & Lie, R. T. (2008). First-trimester maternal alcohol consumption and the risk of infant oral clefts in Norway: A population-based case-control study. American Journal of Epidemiology, 168(6), 638-646.
13. March of Dimes Foundation. (2008b). Professionals & researchers: Folic acid. Retrieved on March 16, 2009, from [http://www.marchofdimes.com/professionals/14332\\_1151.asp](http://www.marchofdimes.com/professionals/14332_1151.asp)
14. United States National Library of Medicine. (2009, January 29). Medlineplus medical encyclopedia. Retrieved March 16, 2009, from [http://www.nlm.nih.gov/medlineplus/ency/presentations/100010\\_3.htm](http://www.nlm.nih.gov/medlineplus/ency/presentations/100010_3.htm)
15. Arizona Department of Economic Security. (2007). Arizona early intervention program. Retrieved March 16, 2008, from <http://www.azdes.gov/azeip/>
16. Arizona Department of Health Services. (2008). Office for children with special health care needs: Children's rehabilitative services. Retrieved March 16, 2009, from [http://www.azdhs.gov/phs/ocshcn/crs/crs\\_az.htm](http://www.azdhs.gov/phs/ocshcn/crs/crs_az.htm)
17. March of Dimes Foundation. (2008a). About us. Retrieved March 16, 2009, from <http://www.marchofdimes.com/aboutus/aboutus.asp>
18. Centers for Disease Control and Prevention. (n. d.). Folic acid: Topic home. Retrieved March 16, 2009, from <http://www.cdc.gov/ncbddd/folicacid/>
19. Arizona Department of Health Services. (2004). Arizona birth defects monitoring program. Retrieved March 16, 2009, from <http://www.azdhs.gov/phs/phstats/bdr/aboutbdr.htm>