Arizona Department of Health Services

Facts about Spina Bifida 1995-2009

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Definition and Types

Spina Bifida is a type of neural tube defect where the spine does not form properly within the first month of pregnancy. There are three types of Spina Bifida: Occulta, Meningocele, and Myelomeningocele.

- Occulta, the mildest form, occurs when there is a division between the vertebrae. However, the spinal cord does not protrude through the back. The spinal cord and the nerve usually are normal. This type of spina bifida usually does not cause any disabilities.
- Meningocele, the least common form, occurs when the covering for the spinal cord but not the spinal cord protrudes through the back. There is usually little or no nerve damage. This type of spina bifida can cause minor disabilities.
- Myelomeningocele, the most severe form, occurs when the actual spinal cord protrudes through the back. The protruding spinal cord and nerve are damaged. This type of spina bifida causes moderate to severe disabilities. [1]

Children with Spina Bifida may have a variety of problems. Some children may need braces, crutches, or wheelchairs since they may not be able to move portions of the lower body. A lack of bowel and bladder control is common in children with Spina Bifida. The build up of fluid in the brain is one complication associated with this birth defect.[2]

ABDMP Data Collection

The ABDMP staff reviews hospital records, birth, and death certificates in order to identify potential cases. After potential cases are identified, the staff review the medical records to confirm that the child is one year old or younger and that they have a reportable birth defect. Once confirmed, information from the abstract is entered into the Arizona Birth Defects Monitoring Program.[3]

United States Estimates

Each year, about 1,500 babies are born with Spina Bifida in the U.S. The lifetime medical cost associated with caring for a child that has been diagnosed with Spina Bifida is estimated at $460,923 in 2009.[4]

In 1992, the Centers for Disease Control and Prevention (CDC) recommended that women of childbearing age consume 400 micrograms of synthetic folic acid daily. Subsequently, the Food and Drug Administration (FDA) required the addition of folate to enriched cereal-grain products by January 1998. Since then, the incident rate for Spina Bifida of post-fortification (1998-2006) was 3.68 cases per 10,000 live births, declined 31% from the pre-fortification (1995-1996) rate of 5.04 cases per 10,000 live births.[4]

Spina Bifida in Arizona

Approximately 34 babies are born in Arizona with Spina Bifida each year. Between October 1998 and December 2009, the average incident rate of Spina Bifida in Arizona decreased (following the folic acid fortification of many cereal foods). The average incident rate of Spina Bifida for all race/ethnicity during the pre-fortification period was 4.41 cases per 10,000 live births. The incident rate of post-fortification was 3.77 cases per 10,000 live births. The incident ratio (post-fortification incident/pre-fortification incident) is 0.85 (95% CI: 0.7-1.01). This 15% reduction in the occurrence of Spina Bifida falls somewhat short of 31% decrease seen nationally.

The incident rate for White (non-Hispanic) was 3.42 cases (95% CI: 1.54-5.30) per 10,000 live births between 1995 and 2009. The rate of Spina Bifida in the Native American and Hispanic population appears to be steady, 3.91 cases (95% CI: 0.08-7.73) per 10,000 live births for Native American and 4.68 cases (95% CI: 2.29-7.08) per live births for Hispanic, respectively. The incident rate for Hispanic is statistically higher than the average incident rate (P=0.002) and the incident rate for White (non-Hispanic) population (P=0.038).

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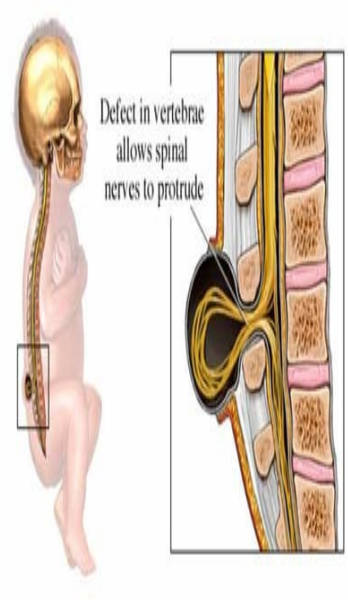
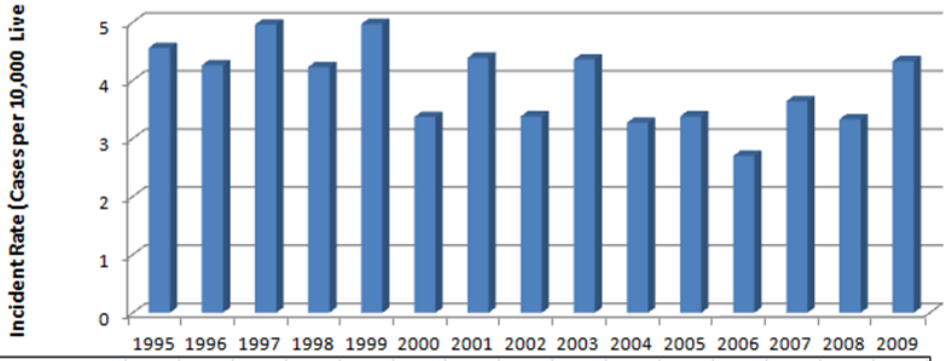
Spina Bifida in Arizona

Figure 1 illustrates the average rate of Spina Bifida for all races in Arizona between 1995 and 2009 was 3.94 cases per 10,000 live births.



A clinical presentation of Spina Bifida.[14]

Figure 1: The average incident rate of Spina Bifida for all races in Arizona from 1995 - 2009

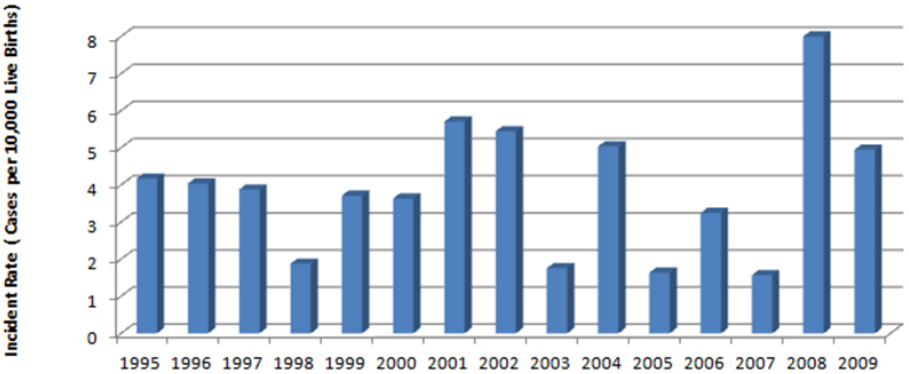


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
All Races Combined	4.56	4.26	4.96	4.23	4.97	3.37	4.39	3.38	4.36	3.27	3.38	2.7	3.64	3.33	4.33
All Races Count	33	32	38	33	40	29	38	30	40	31	33	28	38	33	40

Figure 2: The average incident rate of Spina Bifida in the Native American population between 1995 and 2009 was 3.91 cases per 10,000 live births.

Spina Bifida in Arizona is higher among the Hispanic population.

Figure 2: The incident rate of Spina Bifida for Native American In Arizona from 1995 - 2009



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Native Am	4.17	4.03	3.87	1.87	3.71	3.63	5.7	5.44	1.76	5.04	1.63	3.25	1.57	8	4.95
Native Am Count	2	2	2	1	2	2	3	3	1	3	1	2	1	5	3

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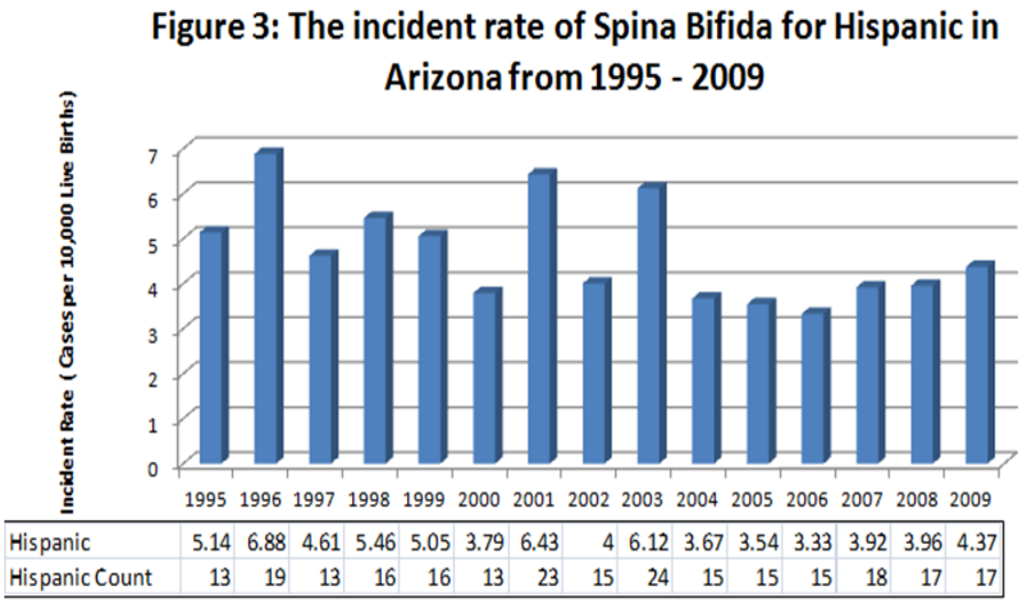
Spina Bifida in Arizona

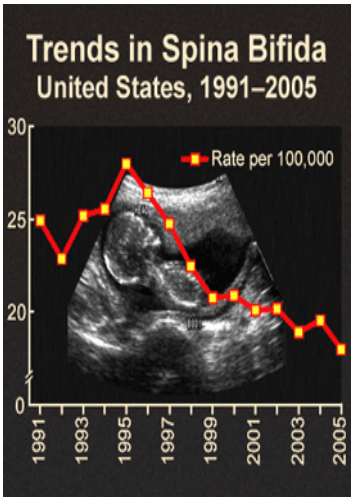
Figure 3: The incident rate of Spina Bifida in the Hispanic population is 4.68 cases per 10,000 Live Births.

Hispanic baby with Spina Bifida .[15]

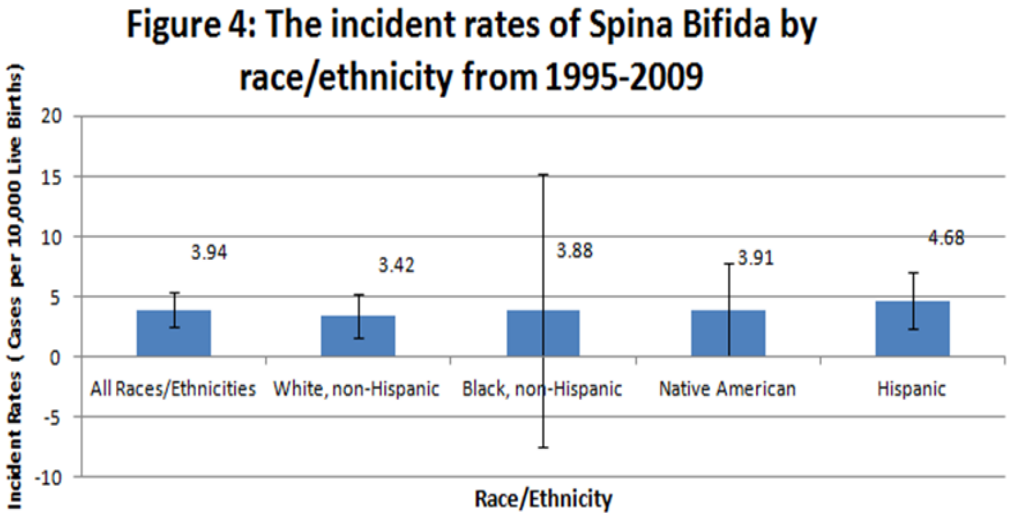


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Hispanic	5.14	6.88	4.61	5.46	5.05	3.79	6.43	4	6.12	3.67	3.54	3.33	3.92	3.96	4.37
Hispanic Count	13	19	13	16	16	13	23	15	24	15	15	15	18	17	17

Figure 4: The incident rate of Spina Bifida by race/ethnicity between 1995 and 2009 including live born and still born infants



The national rate of Spina Bifida has decreased since Post-Folic acid fortification.[16]



Prevention

Folic acid is essentially a water-soluble B vitamin that aids in the production of new cells. Everybody needs folic acid. There is a 31% decline of the incident rate of Spina Bifida since the FDA mandated adding folic acid to all enriched cereal grain products by January 1998. In fact, research has demonstrated that 50% to 70% of neural tube defects (NTD) such as Spina Bifida and Anencephaly can be reduced by taking a folic acid supplement.[5, 6] Hence, it is very important that women of childbearing age take 400 micrograms of folic acid everyday to prevent the NTD.

Folic acid can prevent up to 70% of neural tube defects.

Recognizing that unplanned pregnancies account for 50% of all pregnancies in the United States, the CDC and other organizations recommend that all women of child bearing age take 400 micrograms of folic acid 1-3 months prior to pregnancy.[6, 7] Once women find out they are pregnant, they should increase their folic acid consumption to 600 micrograms. In fact, the March of Dimes Foundation states that most of the prenatal vitamins on the market contain between 800 and 1,000 micrograms of this essential nutrient.[8] Although dietary folic acid can be obtained in foods such as green, leafy vegetables, beans, orange juice, and cereals, people might not get all the vitamins needed from the diet alone. So it is important to take a vitamin with folic acid every day. [9]

Research has also indicated that folic acid may play a role in reversing a nutritional deficiency. Other studies suggested that folic acid might help to prevent some other birth defects, such as cleft lip and palate and some heart defects. [9]

Dietary folate and folic acid can ensure the health of mother and child.[6]

Referral Services

The ABDMP is dedicated to identifying 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.[10]
- 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.[11]
- The Spina Bifida Association (SBA) is a voluntary agency that focuses on serving individuals that live with Spina Bifida. A variety of resources such as research, education, and advocacy issues can be accessed through the SBA.[12]
- The March of Dimes (MOD) is a nonprofit agency that promotes the health of babies by preventing birth defects, prematurity, and infant deaths.[8]

Rehabilitation is an important component to treating children with Spina Bifida .[17]

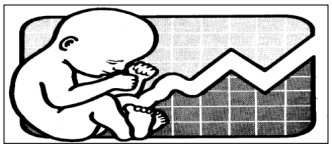
ABDMP Goals

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.[13]

Arizona Birth Defects Monitoring Program



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We are on the web!

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

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