



Spina Bifida in Oklahoma

Spina Bifida, the most common, permanently disabling birth defect in the United States that is also compatible with life in the United States, affects approximately 1,500 births each year. Spina Bifida is a serious and life-long condition that occurs when the spinal cord fails to close properly during the early stages of pregnancy. Approximately 10% of babies born with Spina Bifida do not live into adulthood.

- In Oklahoma, 3.74 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Recent research has estimated that the number of Americans living with all forms of Spina Bifida may be as high as 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 1,362 people with Spina Bifida live in Oklahoma.
- In Oklahoma, there are an estimated 1.1 million women of childbearing age. All are at-risk of a Spina Bifida pregnancy. If women of childbearing age were to consume 400 micrograms (mcg) of the B-vitamin folic acid every day **before pregnancy**, the risk of Spina Bifida and other serious birth defects could be reduced by up to 70%.
- Approximately 1,090 of individuals with THE most serious form of Spina Bifida, myelomeningocele (MMC), suffer from hydrocephalus, a dangerous fluid build-up around the brain, which necessitates surgery to implant a shunt in the brain. Unfortunately, shunts require frequent revisions, and 872 of these devices will fail within 10 years.
- 680 of the people with Spina Bifida in Oklahoma are adults, and 544 of them have MMC. Very little is known about aging with Spina Bifida. Very few physicians are willing to treat people with Spina Bifida or have the knowledge of treatment and interventions associated with its management.

The mission of the Spina Bifida Association is to build a better and brighter future for all those impacted by Spina Bifida

Cost Related to Care for People with Spina Bifida in Oklahoma

- The estimated cost of lifetime care related to Spina Bifida for people with Spina Bifida in Oklahoma is \$866,232,000 though it can often exceed \$1,362,000,000. Among adults with MMC, only about 272 live independently as adults, accruing substantial costs for their lifetime care.
- Out-of-pocket costs for direct medical care for children born with MMC are 13 times more than children born without MMC. These additional costs continue into adulthood when individuals with MMC pay 7 times more in medical costs than those without MMC.
- Family caregivers for people with Spina Bifida are 25% less likely to be employed and, when they are employed, work 25% fewer hours compared to those not providing Spina Bifida-related care.

Clinics:

OU Physicians Urology

(adults)

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<http://www.ou.edu/healthservices.html>

OU Children's Physicians

Pediatric Urology Clinic

(0 - 18)

1200 Children's Ave

Oklahoma City, OK 73104

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