



Spina Bifida in Washington

Spina Bifida, the most common, permanently disabling birth defect that is 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 Washington, an unknown number of babies are born with Spina Bifida because the state keeps no data on it.
- Recent research has estimated that the number of Americans living with all forms of Spina Bifida may be as high as 166,000. Since no data is kept in the state, but by applying the national estimate to the state population, we can estimate that 3,575 people with Spina Bifida live in Washington.
- In Washington, there are an estimated 2.1 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 2,860 of individuals with THE most severe 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 2,288 of these devices will fail within 10 years.
- 1,788 of the people living with Spina Bifida in Washington are adults, and 1,430 of them have MMC. Very few physicians are willing to treat people with Spina Bifida or have the knowledge of treatments 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 the Care of People with Spina Bifida in Washington

- The estimated cost of lifetime care related to Spina Bifida for the 3,575 people living with Spina Bifida in Washington ranges between \$2,273,700,000 and \$3,575,000,000. Among those patients with the most severe form of Spina Bifida, myelomeningocele (MMC), 715 live independently as adults, accruing substantial costs for 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 expenses than those without MMC.
- Family caregivers for Spina Bifida patients 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:

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