



Spina Bifida in Maine

Spina Bifida, the most common, permanently disabling birth defect 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 which occurs when the spinal cord fails to close properly during the early stages of pregnancy. Approximately 10 percent of babies born with Spina Bifida do not live into adulthood.

- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 720 people with Spina Bifida live in Maine. (*data collection period: 2010*).
- In Maine, there are over 400,000 women of childbearing age. All are at-risk of a pregnancy affected by Spina Bifida. 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 percent.
- In Maine, approximately 575 of people 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, thus about 460 of these devices will fail within 10 years.
- In Maine, 360 of the estimated people living with Spina Bifida are adults, and 290 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 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

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Costs Related to the Care of People with Spina Bifida in Maine

- The estimated cost of lifetime care related to Spina Bifida for the 720 people in Maine who live with Spina Bifida can often exceed one million dollars, or \$710,000,000. Among those patients with the most serious form of Spina Bifida, MMC, only half are able to 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 seven times more in medical costs 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 in Maine

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