



Spina Bifida in Wisconsin

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 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 Wisconsin, 2.6 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 1,500 people with Spina Bifida live in Wisconsin.
- In Wisconsin, there are an estimated 1.8 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 1,200 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 960 of these devices will fail within 10 years.
- 750 of the people living with Spina Bifida are adults, and 600 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.

Cost Related to Care of People with Spina Bifida in Wisconsin

- The cost of lifetime care for Spina Bifida patients is \$954,000,000 though it can often exceed \$1,500,000,000. Among those people with MMC, 300 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 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:

Gundersen Health System
Spina Bifida Clinic (**pediatric to transition**)
1900 South Avenue
La Crosse, WI 54601
(800) 362-9567
www.gundersenhealth.org

American Family Children's Hospital
Pediatric Spina Bifida Clinic (**pediatric to 21**)
1675 Highland Ave.
Madison, WI 53792
(608) 263-6420
(800) 323-8942
www.uwhealth.org

Children's Hospital of Wisconsin
Spina Bifida Program (**pediatric to 18**)
9000 W. Wisconsin Ave.
Milwaukee, WI 53201
(414) 266-2690
www.chw.org

Marshfield Clinic (**pediatric to 18**)
1000 N. Oak Ave.
Marshfield, WI 54449
(800) 782-8581
www.marshfieldclinic.org/