



## Spina Bifida in Hawaii

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% of babies born with Spina Bifida do not live into adulthood.

- 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 400 people with Spina Bifida live in Hawaii.
- In Hawaii, there are an estimated 400,000 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 300 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 250 of these devices will fail within 10 years.
- 200 of the people living with Spina Bifida are adults, and 150 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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Community Health Charities #10559

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## **Cost Related to the Care of People with Spina Bifida in Hawaii**

- The cost of lifetime care for people with Spina Bifida is \$1,000,000 though it can often exceed 400,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (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 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.

**\*There are currently no known Spina Bifida clinics for children or adults in Hawaii.**