

**Epidemiology/Genetics Abstracts**

**Title:** POPULATION ESTIMATE OF PEOPLE LIVING WITH SPINA BIFIDA IN THE UNITED STATES, 2004

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**Background:** Spina bifida aperta is among the most common birth defects to affect infants, occurring in approximately 1,300-1,500 births in the United States annually. Much research has been done to ascertain birth prevalence and survival through childhood; however this research has not extended to determine the size of the population of people living with spina bifida. We have developed a method to estimate the number of people living in the United States with spina bifida to address this gap in knowledge.

**Method:** We used two sources of information to develop a population estimate of people living with spina bifida. To estimate the number of people with spina bifida age  $\geq 10$  years, we used estimates from the 1994-1995 National Health Interview Survey on Disability (NHIS-D) of how many people reported having been diagnosed with spina bifida and applied age-specific prevalence estimates to 2004 census estimates. To estimate the population of children with spina bifida age  $< 10$  years, we used birth record data and estimates of birth prevalence and survival. These estimates were then combined to produce a national estimate of people living with spina bifida.

**Results:** Our method produced a national population estimate of approximately 180,000 people living with spina bifida in 2004. It is important to note that this estimate includes people age  $\geq 10$  years who have been diagnosed with spina bifida occulta, who may constitute as many as half of the estimated total, whereas the estimate for children age  $< 10$  years is restricted to those with spina bifida aperta.

**Conclusion:** As babies born with spina bifida experience improved survival and are increasingly living into adulthood, more research is necessary to understand the complete population of people with spina bifida. One such component of this research is determining the size of the population of people with spina bifida, and our method has estimated that there are approximately 180,000 people living with recognized spina bifida in the United States. This estimate provides a starting point for future population-based analyses and to indicate the size of the constituency who need care for spina bifida-related conditions.