

Living with Spina Bifida: Data that Make a Difference

CDC is committed to improving the health of people living with spina bifida. Our data make a difference by giving people with spina bifida the information they need to seek proper care, and by giving healthcare professionals the evidence they need to provide the best care for their patients across the lifespan.



What's the Problem?

About 1,645 babies in the United States are born with spina bifida every year.¹ Spina bifida is a complex condition requiring expensive, lifelong treatment. The estimated lifetime cost of care for a person with spina bifida, with caregiving costs, is \$791,900.²

1. People with spina bifida may require multiple surgeries and hospitalizations.³

2. Bowel and bladder continence are top concerns among people with spina bifida. Bowel and bladder care vary across spina bifida clinics^{4,5}; thus, it is critical to know what works best so that care can be standardized across all clinics.

3. Many young adults with spina bifida experience complex challenges transitioning from pediatric to adult healthcare providers.⁶

What's the Solution?

Research data are yielding new information about living with spina bifida. This research may help people with spina bifida better plan for the care they need, and help healthcare professionals improve care and quality of life for their patients.

1. People with spina bifida and their families need a better understanding of the medical issues they are likely to face during their lives.

- » Data from the National Spina Bifida Patient Registry (NSBPR) can help healthcare providers and families know what surgeries and health issues to expect. Among people with spina bifida, more than half (5 in 10) of all brain and spine surgeries take place before the first birthday. By 18 years of age, at least 8 of 10 lifetime surgeries have taken place.⁷

2. Maintaining bladder and kidney health throughout the lifespan is important for people with spina bifida.

- » Data from the Urologic Management to Preserve Initial Renal Function (UMPIRE) Protocol for young children with spina bifida indicate most infants with spina bifida have healthy bladders and kidneys at birth.⁸ NSBPR data indicate that bladder and bowel care and management vary across spina bifida clinics.^{4,5} Researchers are now looking at the best ways to maintain bladder and kidney health as these infants age.

3. Adolescents and young adults with spina bifida do not always have a successful transition to adult health care. Transition programs vary widely across spina bifida clinics, impacting patients' health and quality of life.⁶

- » NCBDDD is partnering with the American Academy of Pediatrics on a multiyear project to address care coordination between pediatric and adult clinics as patients with spina bifida transition from childhood to adulthood.



Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



For more information



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References

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