

# Spina Bifida Program Overview

Spina bifida is one of the most common permanently disabling birth defects in the United States. Each year, about 1,500 babies are born in this country with spina bifida. The National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC), conducts research to promote the health and improve the lives of people living with spina bifida. Working closely with nonprofit partners since 2003, CDC focuses on addressing mental and physical health, encouraging independence, promoting improved quality of life, and achieving successful adult living.

## Spina Bifida Multisite Study

The goal of this study is to improve the quality of care provided to people living with spina bifida, and help the next generation of families affected by the condition. Findings from this study will be shared with health care providers and families beginning in 2012.

Data gathered from 17 spina bifida clinics across the country will document demographics, care received, and outcomes of that care for children and adults with spina bifida. CDC is the only organization gathering this information at multiple sites in a methodical fashion. Through this study, CDC researchers are learning:

- About the health care services that might be most beneficial to those with spina bifida.
- How factors such as family income and education might impact those with the condition.

## Spina Bifida End-Stage Renal Disease Project

The Spina Bifida End-Stage Renal Disease Project is the first project to look at the connection between the two conditions. Using data from the United States Renal Data System, which includes medical claims and transplant records, CDC research will determine the characteristics of people with spina bifida and end-stage renal disease. CDC researchers will determine whether people with spina bifida are more or less likely to experience health problems and die than people without the condition. This project is part of CDC's work focusing on adults with spina bifida. The study will:

- Identify the age, gender, race, hospitalizations, and history of doctors' visits by people with spina bifida and end-stage renal disease.
- Determine the health care services received by those with spina bifida and end-stage renal disease, comparing services received by those *with* spina bifida to those *without* spina bifida.

The study also will compare the mortality of those with and those without spina bifida who develop end-stage renal disease. The first information from this project will be shared with researchers in 2012, and then be shared with the larger spina bifida community in 2013.



## Spina Bifida in Young Children in Arizona and Utah

This project will include all children with spina bifida in Arizona and Utah, not just those who visit a spina bifida clinic, and will help CDC determine if similar research methods can be used for other rare conditions. CDC researchers will analyze information on children 3 through 6 years of age living in Arizona and Utah. This project will focus on child development and school readiness with the goal of understanding:

- The identification of early learning differences, family environment, mental and physical health, and social skills on children with spina bifida prior to formal education.
- How early behavioral and psychological tests can be done effectively for children who have spina bifida.
- What can be done to reduce learning problems when they are diagnosed at an early age.

Data should be available to researchers in late 2012 and to families in 2013.

## Arkansas Study of Spina Bifida Among Young People

Young people with spina bifida who live into adulthood might experience depression, obesity, social isolation, and lack of independence. The objective of this survey is to determine how frequently these conditions occur and factors associated with them. A detailed survey was administered to individuals 12 through 31 years of age with spina bifida living in Arkansas, and their parents.

The survey for this study included questions about physical factors (such as lesion level, shunt complications, incontinence, and mobility) and environmental factors (such as school experiences and parent-child interactions). The study also looked at sexuality, tobacco and alcohol use, and illicit drug use. From this research, CDC will describe:

- Changes in mobility, incontinence, functional status, and health status over time, using data from a similar survey in 1993 that was given to the same families.
- Health risk behaviors among people with spina bifida, including a possible association with mental health disorders, and implications for caregivers and health care providers.
- Social participation and quality of life among individuals with spina bifida, and factors associated with these outcomes in a real life setting.

Similar to the Arizona and Utah project, this project also focuses on all individuals with spina bifida enrolled in a state registry, not just those seen at spina bifida clinics. The insights gathered could be useful in CDC's work with other complex conditions. Findings from CDC's work will be presented to both researchers and families in 2012.

For more information visit [www.cdc.gov/spinabifida](http://www.cdc.gov/spinabifida) or call 800-CDC-INFO.

