

# What is the National Spina Bifida Program?

2009

2009 was the year the National Spina Bifida Program (NSBP) became a program directed by Congress and housed at the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control (CDC).

Spina Bifida affects  
an estimated  
**166,000**  
Americans

## What does the NSBP do?

There are

4

areas of focus

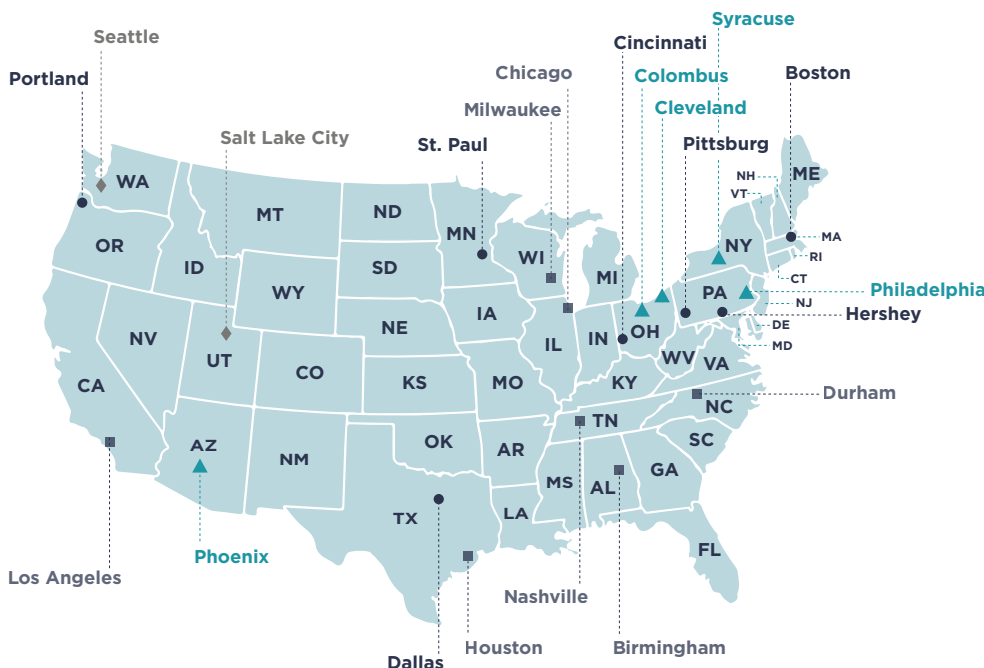
### 20 Registry Clinics

with data on  
10,000 people

The Spina Bifida  
Collaborative Care  
Network developed  
the **Guidelines for  
the Care of People  
with Spina Bifida**

**9 clinics**  
in urologic  
protocol to protect  
kidney health

**Research**  
based on needs  
identified by the  
community



Has the NSBP  
made an impact?

**YES!**

### The National Spina Bifida Patient Registry

collects data to improve  
the quality of care for people  
living with Spina Bifida.  
This data has yielded 24  
publications focused on  
improving care.

**Please support  
the NSBP!**

◆ Site funded by CDC for  
the Urologic Protocol  
for Young Children

● Site funded by  
CDC for the NSBPR

▲ Self-funded  
site for NSBPR

■ Site funded by CDC for the  
NSBPR and the Urologic  
Protocol for Young Children

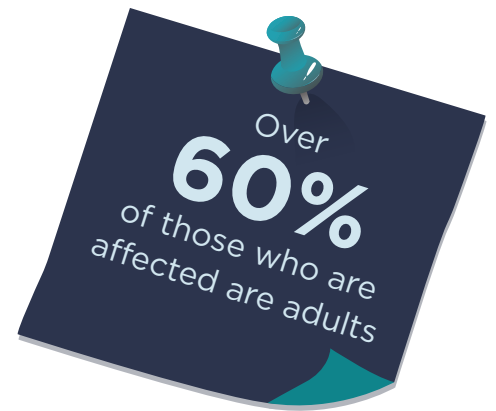
## About SBA

The Spina Bifida Association (SBA), founded in 1973, is the only national voluntary health agency dedicated to Spina Bifida. SBA Chapters and clinics serve more than 125 communities nationwide. This mission of the SBA is to build a better and brighter future for all those impacted by Spina Bifida. The SBA's Strategic Plan sets goals for our work in key areas of Research, Clinical Care, Education and Support, Advocacy, and Network Building.

## Fund the National Spina Bifida Program

Support a \$9 million budget for the National Spina Bifida Program. The program is currently funded at \$7 million. With increased funding we could:

1. Fund research on sudden unexplained death among adults in the Spina Bifida community
2. Develop studies on social determinants of health within the Spina Bifida Registry
3. Create a protocol to improve the health outcomes of children who have Spina Bifida with hydrocephalus
4. Research barriers to transition from pediatric to adult care
5. Analyze potential models for adult care to determine impacts on individual health outcomes
6. Study the effects of Spina Bifida on adults



**SPINA BIFIDA  
ASSOCIATION**

**MARCH 2021**