

What is the National Spina Bifida Program?



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?

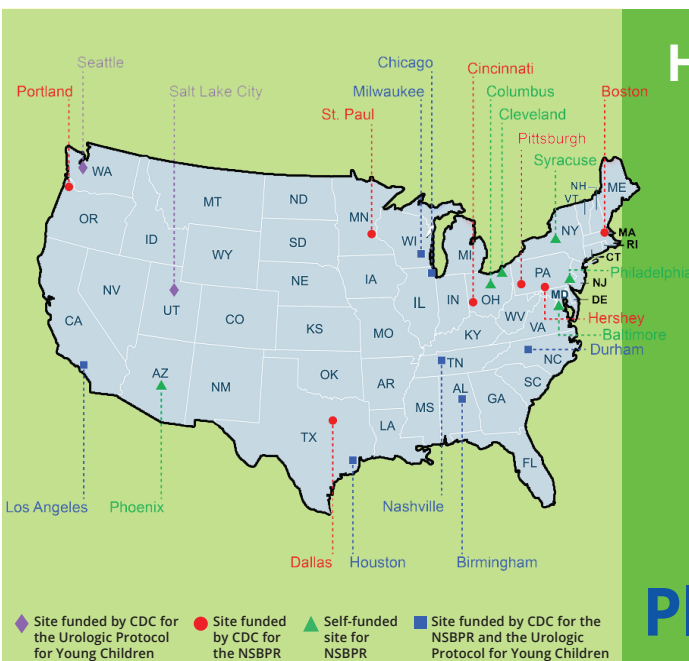
There are **4** areas of focus

24
Registry Clinics
with data on
~10,000 people

The Spina Bifida Collaborative Care Network, **SBCCN**, 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 17 publications focused on improving care.

Please Support the NSBP!

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. In addition, our Strategic Plan sets goals for the Spina Bifida Association in the key areas of Research, Clinical Care, Education and Support, Advocacy, and Network Building.

Why do we need increased funding for the CDC?

We are asking for \$8 million to fund the National Spina Bifida Program. It has been level-funded at \$6 million for the past five years. With this increased funding we will:

- A.** Fund research on sudden unexplained death in the Spina Bifida community
- B.** Determine the number of people living with Spina Bifida in the United States
- C.** Increase clinic participation in the National Spina Bifida Patient Registry
- D.** Develop studies on social determinants of health within the Spina Bifida Registry participants
- E.** Create a protocol aimed at improving the health of those with Spina Bifida and Hydrocephalus
- F.** Research barriers to transition to adult care and analyze models for care delivery for adults with Spina Bifida

Over
60%
of those who
are affected
are adults

~**105**
Pediatric
Clinics

~**21**
Adult
Clinics