



About the Spina Bifida Foundation

In 1999, corporate, union, and community leaders came together with leaders from the Spina Bifida community. Inspired by a need for change and driven by a vision for the future, the Spina Bifida Foundation (SBF) was established as a supporting organization and an active partner of the Spina Bifida Association of America (SBAA).

The SBF was shuttered in 2013. The goals of the Foundation are now being done through SBA's pillars that include Advocacy, Research, Education, and Support.

Goals of the Foundation were to:

Protect Future Generations

Prevention is crucial to ensuring the health and well-being of future generations. The message of the effectiveness of folic acid in reducing the risk of neural tube defects must reach every woman of childbearing age.

Sadly, folic acid is not a magic bullet. Some babies are born with neural tube defects despite folic acid supplementation. The Foundation promoted research into genetic causes of Spina Bifida and worked to identify environmental factors that may increase the risk of Spina Bifida. By learning the causes of neural tube defects, someday, the hope was to act to prevent them effectively.

Plan for a Future Built on Medical Advances

Experts in research, noted members of the medical community and representatives from the Spina Bifida community worked to develop a viable research agenda to ensure the health and well-being of those living with Spina Bifida today and those who may be affected in the future. This group had information from a Congressionally-mandated research conference. The Foundation pursued funding for much-needed research that would benefit the Spina Bifida community.

Change on Capitol Hill

The Spina Bifida Foundation had aggressively defended the wellbeing of those with Spina Bifida through its legislative and funding initiatives.

A significant victory was achieved on behalf of the 70,000 Americans who live with Spina Bifida as a result of the joint efforts of SBF and SBAA when the National Spina Bifida Program was

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established at the Centers for Disease Control and Prevention's (CDC) National Center for Birth Defects and Developmental Disabilities (NCBDDD).

This created a comprehensive, federally funded programmatic initiative that addressed primary prevention and worked to improve the quality of life for those affected.

A Better Future

Together the Spina Bifida Association of America and the Spina Bifida Foundation worked to secure a better life for those who live with Spina Bifida.