Support and Programs

Those impacted by Spina Bifida can request assistance for addressing challenges and achieving goals on a short or long-term basis.

Contact the office to Request:

-Information and education

-Individual, peer, and group support

-Financial scholarships

-Welcome packets for new families

-Self and systems advocacy

-Connections to healthcare and service providers, along with clinic collaborations

-Assistance with referrals and navigating systems, including insurance, transportation, transition, employment, special education, housing, benefits, equipment, and disability services.

SBANYS offers a host of hybrid in-person and virtual opportunities to receive education, networking, and support. Examples include:

-Employment training program for young adults

-Community trainings to direct support providers, healthcare professionals, and the general public

-Adult support group

-Peer support network

-Annual educational conference

-Regional family friendly programming

Our Vision: We envision a world where everyone impacted by Spina Bifida is accepted and thrives.

Our Values: Support, Health & Wellness, Awareness, Respect & Dignity, and Empowerment.

Our key service areas are clinical care, education and awareness, advocacy, and programming.

"SBANYS has been a cornerstone of support and advocacy for individuals and families in the Spina Bifida community. Through its programs and services, SBANYS fosters inclusion, provides valuable resources, and empowers individuals to lead fulfilling lives. Personally, it has been a source of inspiration and connection, offering guidance and a sense of community that has truly enriched my life." *-Eddie, an adult with Spina Bifida*

SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

Building a better and brighter future for all those impacted by Spina Bifida

Website: www.sbanys.org

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What is Spina Bifida?

Spina Bifida is the most common permanently disabling birth defect that is compatible with life. There are approximately 166,000 individuals in the United States who have Spina Bifida. It's a type of birth defect that occurs when a baby's neural tube fails to develop or close properly – the literal meaning for Spina Bifida is "split spine." Spina Bifida occurs within the first 28 days of pregnancy while the neural tube is forming and often before someone knows they are pregnant. Spina Bifida is commonly referred to as a "snowflake condition" because no two cases are the same as Spina Bifida can range from mild to severe. The severity depends on everything, from the size of the opening to the location on the spine.

Although no two cases of Spina Bifida are identical, there are three main types of Spina Bifida which are the most common, each of which have treatment options to help individuals reach their full potential.

-Myelomeningocele: Sac of fluid on the baby's spine that can be open or closed, with nerves exposed.

-Meningocele: Sac of fluid on the baby's spine where the nerves do not protrude into the sac.

-Occulta: Most mild and rare form of Spina Bifida, with a potential small gap in the spine and minimal symptoms.

How does Spina Bifida affect people?

Lifespan: Babies born with Spina Bifida today are typically expected to live long lives due to medical advancements. Many factors affect life expectancy, such as other conditions the baby may be born with, and the healthcare they receive throughout life. Spina Bifida itself is not a condition that causes active physical decline, but its effects on the body can change with growth and secondary health issues.

Secondary Health Issues Include:

-Mobility

-Neurogenic Bladder and Bowel

-Hydrocephalus

-Executive Functioning

Independence: Most people can become independent with their own care with training and encouragement. Working with a team of doctors, nurses, social workers, teachers, support organizations, and other families, together can often lead to good outcomes in independent living, employment, and other measures of quality of life.

Who are we?

The Spina Bifida Association of New York State (SBANYS) is a not-for-profit organization whose mission is to build a better and brighter future for all those impacted by Spina Bifida. With that in mind, our goal is to meet that mission through three main areas of service: Support, Education, and Advocacy. Within these areas you will find services that include, but are not limited to: responding to requests for information/referrals, education outreach, advocacy and awareness initiatives, peer support, systems navigation, and programming.

Our services are available statewide, at no cost, and benefit the 4,000 individuals living with Spina Bifida across the lifespan in NYS.

Our History:

The association was formed in 1993 by a small group of local parents whose children were born with Spina Bifida. This core group of parents met through a local Spina Bifida clinic and volunteered to support a handful of local families in the Capital District. In 2018 the association hired their first full-time Executive Director. In 2022, the association officially changed its service area from Northeast New York to all of New York State to meet the scope of consumers and services provided, and officially updated its name to Spina Bifida Association of New York State.