Our Mission: To promote the prevention of Spina Bifida and enhance the lives of all affected.

Our Vision: We envision a world in which people living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not impeded by Spina Bifida and all experience rich and personally fulfilling lives.

Our Value Statement:
Our purpose is
  Support
  Health & Wellness
  Awareness
  Respect & Dignity
  Empowerment

Our History: SBA of NENY was formed in 1993 by a small group of local parents whose children were born with Spina Bifida. Since then, the organization has grown, now serving over 300 families, including adults with Spina Bifida, young children and their parents, spouses and grandparents. The current Board of Directors contains parents of children living with Spina Bifida, adults with Spina Bifida, and community members.
Spina Bifida is the most common permanently disabling birth defect compatible with life in the United States yet most people do not know what it is.

Jessica Ryder shared, “when I received Charlie's Spina Bifida diagnosis in-utero, I had no idea where to go. My mom is a midwife and she was not aware of what existed locally to support someone in my position. There was this huge lack of awareness and when I began discussing Spina Bifida with providers, my initial sense was my child's quality of life was going to be diminished. The first person I met living with Spina Bifida was Heather and the first thing she did was let me know we would get through this together, and that Charlie was going to have a good quality of life.”

Through the peer support network, Spina Bifida Association of Northeastern New York (SBANENY) provides connections like these for expectant parents, parents of youth and teens, grandparents, and adults living with Spina Bifida. In New York State, there is an estimated 10,000 individuals living with Spina Bifida. As the only Spina Bifida Association affiliate in New York State, individuals living with Spina Bifida and their families benefit from these connections with peers which offers information, resources, and support.

Heather stated, “Charlie will have a good quality of life! I was able to go to college, I am employed, I volunteer and spend time with family and friends. But there will be challenges. I have to regularly educate the people in my life about what Spina Bifida is and this affects your experiences and your ability to receive quality care and services.”

Through community outreach and social media, SBANENY raises awareness about Spina Bifida and connects with new individuals and families. Once a family is connected with SBANENY, they receive information, referral, system navigation, education, support, advocacy, and programming services to address the unique challenges associated with Spina Bifida.

This is not possible without you! SBANENY achieved many great accomplishments in 2018 as a result of your support. Continue reading to learn about how SBANENY utilizes your support to provide programs and services for the individuals and families living with Spina Bifida.
Education Day Highlights

- **Expanded education to youth and teens, including a Spina Bifida Fashion Show**
  
  Youth and teens living with Spina Bifida received an outfit from a selection of adaptive Tommy Hilfiger clothing donated by Runway of Dreams and received hair and makeup styling before walking and rolling down the runway.

- **48 individuals ranging in age from 18 months to 60 years old**
  and their family members traveled from within New York State and from three outside states to attend the Education Day.

- **30% of individuals and families in attendance benefitted from SBANENY sponsored scholarships** supporting travel, lodge, and registration.

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SBANENY hosted the 5th Biennial Education Day providing comprehensive updates in healthcare and community services. **SBANENY recruited two nationally renowned experts in Spina Bifida care** to present to the individuals and families living with Spina Bifida. Both Dr. Levey and Dr. Zabel came to us with 15 years+ experience working with people with Spina Bifida at Kennedy Krieger Institute in Baltimore, MD.

**Eric Levey, M.D.** is a pediatrician specializing in the medical care of children with severe developmental disabilities who presented on urology, bowel management and transition to adulthood.

**T. Andrew Zabel, Ph.D., ABPP** is a clinical neuropsychologist who presented on executive functioning and Spina Bifida and transition to adulthood.

"The SBANENY conference was a wonderful opportunity for me to acquire important information on aging with Spina Bifida. The national speakers had decades of experience which they shared both in the formal workshops as well as one on one. The conference also identified local resources which have proven helpful in addressing challenges that come about as a result of living with Spina Bifida. I am looking forward to the next conference in Spring 2020!"
Information & Awareness

Spina Bifida Education
Through a grant funded by Hanger, Inc. SBANENY shared packages containing information on Spina Bifida, SBANENY and the relationship between folic acid and neural tube defects such as Spina Bifida with 200 Women, Infant & Children Center’s across New York State.

Advocacy
Volunteers and SBANENY staff participated in annual visits with New York State representatives to provide updates on the experiences and challenges of the Spina Bifida community.

Social Media
♦ SBANENY created an Instagram account to expand on how individuals living with Spina Bifida, their families and friends receive information and updates related to the Spina Bifida community.

  www.facebook.com/SBANENY  www.instagram.com/spinabifidaassoc_neny

♦ SBANENY created two private Spina Bifida Facebook groups to facilitate connections between individuals and families.

  ♦ With 64% of NYS residents living in Metro NYC, SBANENY created a group for parents of children and adults living with Spina Bifida in Metro NYC and surrounding counties to share local information and resources.

  ♦ After spending a 3-day weekend with 20 families with children living with Spina Bifida ages 5-21 at Double H Ranch, SBANENY created a group for the parents to allow for further networking, information, and resource sharing.

♦ During the awareness month of October, SBANENY shared 31 posts about Spina Bifida reaching 25,800 people.

SBANENY celebrates 25 years of service in 2018.

In 1993, parents of children living with Spina Bifida worked together to establish a local Spina Bifida chapter. In 2018, we honored our founders at SBANENY’s annual gala for the hard work, dedication, and support to the Spina Bifida community that started 25 years ago and continues today.

A copy of Spina Bifida Association of Northeastern New York’s annual report may also be obtained, upon request, from the Office of the Attorney General, Charities Bureau, 120 Broadway, New York, New York 10271.
It was an exciting year for the development and expansion of programs and services.

Case Management Services
- Information & Referral
- Advocacy
- Support
- Education
- Increased one-on-one opportunities for case management services to support individuals in navigating systems such as healthcare, benefits, and employment.

SBANENY Internship Program
- Providing paid employment experience and training for teens and young adults living with Spina Bifida to prepare for new or greater employment opportunities.
- SBANENY had the first ever graduation from the internship program to greater employment in 2018!

Peer Support Network
- Connecting parents, grandparents, and adults living with Spina Bifida via cellphone, social media, and email to offer resources and support.

Equipment Exchange
- SBANENY families seeking to donate or receive equipment that will assist the individual with their activities of daily living.

Fall Family Retreat at Double H Ranch
- SBANENY added an “ask the adult” focus group to allow parents to discuss transitioning to adulthood with adults living with Spina Bifida and parents of adult children.

Program Outreach and Development
- SBANENY shared 300 surveys with individuals living with Spina Bifida and their caregivers to assess programming and service needs in the Spina Bifida community.

To learn more about SBANENY programs and services, contact the office today!
Tel: 518-399-9151
## 2018 Financial Report

### Balance – December 31, 2017

$131,966

### Revenues

- Fundraisers: 70,159
- Donations: 8,527
- Grants: 15,686
- Interest and dividends: 10,081
- Other Income: 6,150

**Total Revenues**: 110,603

### Expenses

- Program: 68,790
- Fundraising: 21,242
- Administration: 8,646
- Insurance: 3,758
- Depreciation: 1,174
- Professional Fees - Accounting: 2,100

**Total Disbursements**: 105,710

### Investment Performance

- Net appreciation in investments: (19,204)
- Gains from sale of investments: 5,918

**Net Investment Loss**: (13,286)

### Balance – December 31, 2018

$123,573
Spina Bifida Association of Northeastern New York
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518-399-9151
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www.sbaneny.org

Staff
Executive Director, Julia Duff, LMSW

2018 Board of Directors
Margaret Smith, Chair
Tracy Paige, Vice Chair
Michelle Miller, Immediate Past Chair
James Alescio, Treasurer
Margaret Felt, Secretary
Kevin Chamberlain
Robert Derrick
James Dunham
Annnmarie Fennicks
Margaret Huff
Lyndsi Holmes-Wickert
Gloria Zampini

Thank you to the 2018 SBANENY volunteers and supporters who helped make this all possible!

JOIN THE TEAM!
If you are interested in offering your support and expertise to the Spina Bifida community, contact the Spina Bifida Association of Northeastern New York to learn more about our Board of Directors, Professional Advisory Committee, or one of our volunteer committees!