The Spina Bifida Association of Northeastern New York serves individuals of all ages with Spina Bifida and their families. Our service area is northeastern New York State, but as the only chapter of the National Spina Bifida Association in New York, we also respond to calls from individuals and their families throughout the State and the surrounding areas. That is why we need your support.

Our mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected. We serve families including adults with Spina Bifida, young children and their parents, spouses, and grandparents. Our staff of two part-time people together with more than eighty volunteers work hard to meet the needs of the growing number of people requesting services. Some of the services provided by the chapter include information and referral, support, advocacy, awareness, and educational programs. The SBANENY staff also serves as a resource to other service and health care providers in the community.

In addition to the services mentioned above, the Spina Bifida Association also provides programs designed to facilitate peer support, networking, and opportunities to enjoy community events.

In order to continue to provide these services, we need your support. This year is a milestone year as we celebrate the 25th anniversary of the organization. If you have given in the past, thank you! If you haven’t, why not consider giving this year as a way to honor all of the wonderful things that SBANENY has done and continues to do to enhance the lives of those living with Spina Bifida.

Best wishes to you and yours for a wonderful holiday season.

Peggy Smith, Board Chair

Our Purpose Is
Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment
Information & Education

- Quarterly newsletters reached over 1500 households with information about Spina Bifida, health and people with disabilities, employment, taxes, navigating benefits and insurance, and resources in the community.
- SBANENY’s paid Internship Program provided 447 hours of skill building work experience to individuals with Spina Bifida.
- Bi-weekly outreach containing information about adaptive sports and active healthy lifestyles reached over 12,000 contacts. Instructional opportunities included an adaptive dance workshop and adaptive sailing.
- Consumers and SBANENY staff attended a conference in Baltimore, MD, hearing presentations by nationally recognized health care experts, and returning to New York State to share the information learned.

Awareness

- Adaptive Dance demonstration held during Dare to Dream with SBANENY, raised awareness among the guests about the possibilities of physical activity, particularly through dance, for people living with disabilities.
- SBANENY’s social media reach in 2017 increased by more than 260% from the previous year.
- A team of SBANENY staff and volunteers participated in annual visits to community leaders and elected state and federal officials to raise awareness about Spina Bifida and the needs of this community.
- Quarterly community events were staffed to raise awareness about Spina Bifida.
- All known individuals and families living in NYS received a SBANENY survey. The results provided an assessment of needs and information for future program development.

"SBANENY has helped me to find health care providers who know about Spina Bifida and can meet my needs. The staff worked with me to learn to better prepare for my doctor appointments and to express my needs more clearly. Now with these resources and skills, everything that I need gets addressed."

Julia Duff, LMSW       Executive Director

2017 Board of Directors
Michelle Miller, Chair  Heather Green-Kirk
Margaret Smith, Vice Chair  Kevin Chamberlin
Lyndsi Holmes-Wickert, Past Chair  Margaret Huff
James Alescio, Treasurer  Gloria Zampini
Margaret Felt, Secretary  James Dunham
Annmarie Fennicks
Connections

- The SBANENY Peer Support Network, facilitated by the staff, connects parents and adults with each other to share information and experiences as one method to provide support. Over 100 outreach contacts were made to connect 15 peer support individuals and families to consumers requesting this service.

- SBANENY programs reached over 450 children, parents, and adults living with Spina Bifida.

- Parents and children had opportunities to “ask the adult” questions about challenges related to growing up with Spina Bifida during fall family programming.

- In 2017, SBANENY saw over a 30% increase in requests for our case management services.

Outreach

Through the dedicated work of two staff people and over 80 volunteers;

- SBANENY connected with welcome information and follow up services to 43 new families;

- SBANENY programs reached over 450 children, parents, and adults living with Spina Bifida.

- Parents and children had opportunities to “ask the adult” questions about challenges related to growing up with Spina Bifida during fall family programming.

- In 2017, SBANENY saw over a 30% increase in requests for our case management services.

Financial Report

Balance - December 31, 2016 $152,633

Revenues
- Fundraisers 60,155
- Donations 10,254
- Grants 9,815
- Interest & Dividends 9,985
- Other Income 2,486
Total Revenues 92,695

Expenses
- Program 96,621
- Fundraising 13,352
- Administration 9,666
- Insurance 3,421
- Depreciation 1,224
- Professional Fees 2,043
Total Disbursements 126,327

Investment Performance
- Net appreciation in investments 4,615
- Gains from sale of investments 8,350
Net Investment Gain 12,965

Balance - December 31, 2017 $131,966

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.