2019 ANNUAL REPORT

NORTHEASTERN NEW YORK
“When did you get Spina Bifida?” Mary recalls a neurology resident asking her this question during the introduction of a doctor’s appointment. The only thing she could respond with was: “You don’t get Spina Bifida, you are born with it.”

Mary now discusses this instance with humor but states the shock felt in that room: “How can a neurology resident not know that Spina Bifida is a neural tube defect?” Concerned, distrustful, and overwhelmed are just some of the emotions an individual with Spina Bifida feels when they realize that a medical professional does not understand the basics of Spina Bifida.

Mary is an adult with Spina Bifida and unfortunately, this experience is not unique. The Spina Bifida Association of Northeastern New York (SBANENY) has heard time and again variations of this story from adults living with Spina Bifida, parents of a child with Spina Bifida, grandparents, and expectant parents. At SBANENY, we recognize the lack of awareness and understanding about Spina Bifida in the general population is also prevalent in the medical profession.

Through advocacy and education, SBANENY is taking steps to improve healthcare experiences and outcomes for people with Spina Bifida. This includes...

- Connecting individuals and families living with Spina Bifida to experts in the field.
- Providing up to date guidelines and best practices in medical care to support self-advocacy in doctor’s appointments.
- Raising awareness about Spina Bifida by meeting with providers caring for the community.

SBANENY cannot do this without the support of our families, donors, volunteers, and business partners. Thank you to all of our contributors in 2019. To learn more about how your support turned into expanded programs and services for individuals and families living with Spina Bifida, continue reading the 2019 Annual Report.
Information & Education

Education Outreach

- Quarterly newsletters sent to 1,200+ contacts with Spina Bifida information and resources:
  - Scholarships, self-advocacy, healthcare updates, education opportunities, transportation, equipment, research, housing, and SBANENY events.
- Monthly E-News distributed to individuals living with Spina Bifida, their caregivers, and family members across New York State.
- Highly active on social media totaling 300 posts. Be sure to follow us on: 

  [SBANENY](https://www.facebook.com/SBANENY)
  [Spinabifidaassoc_neny](https://www.instagram.com/spinabifidaassoc_neny)

SBANENY newsletters are available in electronic and print versions. Contact admin@sbaneny.org to sign up to receive SBANENY updates!

Community Training

SBANENY taught a seminar at the YMCA Glenville Branch for the Counselors-In-Training (CIT) Program. Attendees were educated on:

- Spina Bifida
- Employment and disability
- Environmental barriers for wheelchair users

SBANENY Scholarships

- SBANENY sponsored financial scholarships for individuals with Spina Bifida pursuing higher education and training.
- Congratulations to Madeline White, the 2019 recipient of the Frank Bucino Jr. Memorial Scholarship and Helen R. Mertens Educational Scholarship as she pursues a degree in Occupational Therapy!
- Scholarship guidelines and applications are available at www.sbaneny.org.
New York State Advocacy

- SBANENY staff and consumer advocates met with 20 New York State Legislators to educate them on Spina Bifida and SBANENY services.

- **Spina Bifida Awareness Month in October was officially recognized with an introduction on the New York State Assembly floor by Assemblymember John McDonald III.**

- Spina Bifida Awareness Month resolutions were passed in both the New York State Senate and Assembly.

National Advocacy

- **SBANENY participated in the 2nd Annual Teal on the Hill event** where SBANENY Executive Director and 100+ advocates from around the country traveled to Washington, D.C. and met with over 75 members of Congress from 27 states.

- Representatives were educated on the gaps in Spina Bifida care and the importance of supporting the National Spina Bifida Program that guides research for individuals living with Spina Bifida across the lifespan.

October is Spina Bifida Awareness Month!

- SBANENY staff visited with Ann Parillo on Schenectady Today to raise local awareness about Spina Bifida and our annual awareness campaign.

- Executive Director Julia Duff and SBANENY Board Chair Lyndsi Holmes-Wickert were interviewed on the morning news by Jill Konopka from WNYT Channel 13, reaching hundreds of viewers with awareness education.

- SBANENY shared daily social media posts with Spina Bifida facts and personal experiences from individuals living with Spina Bifida.
SBANENY increased consumer services by 10% in 2019.

- SBANENY welcomed our first Master’s level intern from the SUNY at Albany School of Social Welfare program to assist with case management services.

“It was a huge help having SBANENY’s Social Welfare Intern available to support me, especially with housing. She assisted me with researching potential apartments, preparing for visits to assess accessibility, and navigating confusing systems. This hands-on support was a great addition to SBANENY case management services!”

SBANENY advocated with medical providers at Albany Medical Center to reestablish the Pediatric Spina Bifida Clinic.

- SBANENY and parents of children with Spina Bifida provided a training to participating clinic providers on the current medical experiences of people in the Spina Bifida community.

- Collaborated with Pediatric Department Chair Dr. Barbara Ostrov, Urology Department Chair Dr. Barry Kogan, and Director of the Spina Bifida Clinic Dr. Matthew Adamo to institute a comprehensive clinic.

SBANENY annual programs offered support, education and connections.

- Programs reached individuals with Spina Bifida ages 2-60 years old.

- **Over 500 individuals and families** participated in SBANENY’s 2019 programs.

- 90 individuals, siblings, parents and caregivers of individuals with Spina Bifida attended the Fall Family Retreat at Double H Ranch.

  - **SBANENY added three new support sessions:**
    - The Bus Stop Club hosted a therapeutic activity for siblings of campers with Spina Bifida.
    - Adult volunteers with Spina Bifida facilitated two support chat groups for youth and teens.
## 2019 Financial Report

### Balance – December 31, 2018

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revenue</td>
<td>$123,573</td>
</tr>
<tr>
<td>Expenses</td>
<td>$104,295</td>
</tr>
<tr>
<td>Investment Performance</td>
<td></td>
</tr>
<tr>
<td>Gain (loss) from sale of investments</td>
<td>253</td>
</tr>
<tr>
<td>Unrealized gain (loss) on investments</td>
<td>19,125</td>
</tr>
<tr>
<td>Net Investment Gain (Loss)</td>
<td>19,378</td>
</tr>
<tr>
<td>Balance – December 31, 2019</td>
<td>$136,211</td>
</tr>
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### Revenue

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Fundraising</td>
<td>72,768</td>
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<tr>
<td>Donations</td>
<td>9,569</td>
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<tr>
<td>Grants</td>
<td>6,578</td>
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<tr>
<td>Interest and dividends</td>
<td>7,611</td>
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<tr>
<td>Other Income</td>
<td>1,029</td>
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<tr>
<td><strong>Total Revenue</strong></td>
<td>$97,555</td>
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### Expenses

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
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<tr>
<td>Programs</td>
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<tr>
<td>Fundraising</td>
<td>33,129</td>
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<td>Administration</td>
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<td>Insurance</td>
<td>3,841</td>
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<td>Depreciation</td>
<td>1,138</td>
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<td>Professional Fees - Accounting</td>
<td>2,100</td>
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<tr>
<td><strong>Total Disbursements</strong></td>
<td>$104,295</td>
</tr>
</tbody>
</table>

### Investment Performance

- Gain (loss) from sale of investments: $253
- Unrealized gain (loss) on investments: $19,125

### Net Investment Gain (Loss)

<table>
<thead>
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<tr>
<td>Net Investment Gain (Loss)</td>
<td>$19,378</td>
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</tbody>
</table>

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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.
Our Mission: To build a better and brighter future for those impacted by Spina Bifida.

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: SBANENY 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.

Give today at www.sbaneny.org.

Interested in supporting SBANENY services for individuals living with Spina Bifida?

- Sign up to become a monthly donor.
- Attend our annual fundraising events.
- Sign up to receive SBANENY donation appeals.
- Celebrate your birthday with SBANENY on Facebook.
- Recycle with SBANENY through Clynk.
- Discuss matching gifts with your employer.
- Request a sponsorship from your place of work.
- Host a 3rd Party Fundraiser.

DONATE HERE!
Staff
Executive Director, Julia Duff, LMSW

2019 Board of Directors
Lyndsi Holmes-Wickert, Chair
Tracy Paige, Vice Chair
Margaret Smith, Immediate Past Chair
James Alescio, Treasurer
Michelle Miller, Secretary
Kevin Chamberlain
Chris Darby-King
Robert Derrick
Helen Eggenberger
Margaret Felt
Gloria Zampini

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 Council, or one of our volunteer committees!