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

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

Our Value Statement: Our purpose is

- Support
- Health & Wellness
- Awareness
- Respect & Dignity
- Empowerment

Our History: SBANENY was formed in 1993 by a group of local parents whose children were born with Spina Bifida. Initially serving a handful of families, SBANENY now reaches thousands of people impacted by Spina Bifida including individuals living with Spina Bifida, their caregivers, families, and support network of providers. Members of SBANENY’s Board of Directors include parents of children living with Spina Bifida and adults living with Spina Bifida, effectively rooting us in our family focused foundation to pursue our mission.
Education Outreach
SBANENY distributes Spina Bifida information and resources via email, social media, and newsletter, all available on the SBANENY website.

Educational Email News
◊ Monthly email news shared with over 300 individuals and families

SBANENY Newsletter
◊ Quarterly newsletters shared with over 1,300 contacts including consumers, legislators, healthcare and service providers

Social Media
◊ Daily outreach with over 1,000 followers

SBANENY Scholarships
SBANENY offers two scholarships for individuals living with Spina Bifida to provide financial assistance for training, conference attendance, and higher education.

Frank Bucino Jr. Memorial Scholarship & Helen Mertens Educational Scholarship

Sam Rivers was awarded both of these financial scholarships to support his pursuit of a degree in Radiation Therapy degree from Upstate Medical University.
Legislative Advocacy
SBANENY advocates annually with New York State (NYS) and national representatives to provide education about Spina Bifida and SBANENY programs and services.

◊ SBANENY and consumer advocates met with 30 NYS Assembly Members and Senators

◊ The 3rd annual resolution officially recognizing October as Spina Bifida Awareness Month was passed by the NYS Assembly and Senate

◊ For the 2nd year in a row, SBANENY advocated with U.S. Congress members and Senators at the national Spina Bifida Association’s 3rd annual Teal on the Hill event

◊ NYS funding for SBANENY programs and services was included in the Aid to Localities Bill through the NYS Department of Health for the first time in SBANENY’s history

Individual and Family Advocacy
SBANENY promotes self-advocacy and advocates with consumers for equal access to quality medical care, support services, and activities of daily living.

◊ Responded to over 300 requests from consumers seeking self-advocacy information and support

◊ A team of consumers attended meetings with NYS representatives and shared stories about living with Spina Bifida, barriers to independent living, and common health challenges
Spina Bifida Clinic at Albany Med
SBANENY collaborates with Albany Med to support individuals living with Spina Bifida to receive comprehensive and coordinated healthcare across the lifespan.

◊ SBANENY offered information and support to families in attendance at the pediatric Spina Bifida Clinic at Albany Med prior to COVID-19

◊ SBANENY informed all known consumers when Albany Med established their first ever Adult Spina Bifida Clinic—only 1 out of 28 to exist in the country!

Health & Wellness Series, October 2020
SBANENY instituted a brand new wellness series to address the healthcare needs of consumers resulting from the pandemic.

◊ Developed Spina Bifida Health & Wellness Reminder Checklists in partnership with the National Spina Bifida Association. The checklists provide critical healthcare reminders and were shared on a national level reaching thousands of individuals and families living with Spina Bifida

◊ Facilitated 3 webinars on mental health, adaptive fitness, and urological updates during Spina Bifida Awareness Month, reaching over 100 families living with Spina Bifida in NYS
AWARENESS

Visibility
◊ Increased consumers receiving services by 3%
◊ Increased social media reach by 6%

COVID-19 Education
As the hub of Spina Bifida expertise in NYS, SBANENY quickly responded to COVID-19 by sharing information and resources pertaining to the Spina Bifida community.

◊ Distributed monthly emails with information on vulnerable populations, home and community based services, accessing healthcare, systems and benefits changes, and mental health resources to support consumers as they navigated the pandemic

Expanded Connections to Local Colleges

SUNY Albany

◊ SBANENY welcomed our 2nd intern through the SUNY Albany Master’s in Social Welfare program to supplement SBANENY’s individual and family services

◊ A panel of SBANENY consumers and staff celebrated the 30th anniversary of the passing of the Americans with Disabilities Act (ADA) by presenting its history and impact during SUNY Albany’s Learning from Alumni Series

Siena College

◊ SBANENY welcomed undergraduate students from the Siena Bonner Service Program. Bonner Service Leaders utilize their academic skills to provide in-kind service to nonprofits like SBANENY. Bonner students have assisted with the outreach and implementation of SBANENY events.
Virtual Programming
In March 2020, SBANENY transitioned our annual programs and services to a virtual format to ensure consumers received stable and consistent support. This new platform increased the ability of consumers to attend and participate across NYS.

As a result, SBANENY:
◊ Tripled the frequency of programs
◊ Expanded the reach of our programs across NYS
◊ Increased the number of consumers in attendance

2020 Virtual Programs

◊ 10 peer-support programs for adults living with Spina Bifida

◊ 7 webinars providing updates on virtual learning, advocacy, healthcare and developmental disability services

◊ 5 programs for young families living with Spina Bifida offering peer support and opportunities to “ask the adult”

SBANENY Employment Training Program

After closing the office in March, SBANENY instituted remote internships which expanded opportunities to gain new skills, learn new tasks, and complete tasks with greater independence
SBANENY responded to over 2,500 requests for information and referrals, support, advocacy, and systems navigation and welcomed 13 new families to the SBANENY community. As the only affiliate chapter of the national Spina Bifida Association in NYS, SBANENY responds to requests for support and information and invites consumers across NYS to programs.

Where individuals and families are located

Who SBANENY serves

Types of services being provided
### 2020 Financial Report

<table>
<thead>
<tr>
<th><strong>Balance – December 31, 2019</strong></th>
<th><strong>$ 136,211</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>63,976</td>
</tr>
<tr>
<td>Donations</td>
<td>7,260</td>
</tr>
<tr>
<td>Grants</td>
<td>15,227</td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>4,591</td>
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<tr>
<td>Other Income</td>
<td>325</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>91,379</strong></td>
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<tr>
<td><strong>Expenses</strong></td>
<td></td>
</tr>
<tr>
<td>Programs</td>
<td>44,172</td>
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<tr>
<td>Fundraising</td>
<td>12,900</td>
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<tr>
<td>Administration</td>
<td>11,071</td>
</tr>
<tr>
<td>Insurance</td>
<td>4,045</td>
</tr>
<tr>
<td>Professional Fees - Accounting</td>
<td>2,100</td>
</tr>
<tr>
<td>Depreciation</td>
<td>95</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>74,383</strong></td>
</tr>
</tbody>
</table>

#### Investment Performance
- Gain (loss) from sale of investments: **27,523**
- Unrealized gain (loss) on investments: **(13,168)**

**Net Investment Gain (Loss):** **14,355**

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<tr>
<th><strong>Balance – December 31, 2020</strong></th>
<th><strong>$ 167,562</strong></th>
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**Revenue**
- Interest & Dividends: 5%
- Donations: 8%
- Grants: 17%
- Other Income: <1%

**Expenses**
- Programs: 60%
- Fundraising: 17%
- Professional Fees - Accounting: 5%
- Insurance: 4%
- Administration: 15%
- Depreciation: <1%
WHY DO YOU GIVE?

“I was born with Spina Bifida and as I age my needs change. It is important that I continue to have a source for the most up to date medical information as well as maintaining connection with peers and staff who support and encourage healthy lifestyles. SBANENY is the only organization in this region solely dedicated to the Spina Bifida community.”  - Barb Devore

10 WAYS TO GIVE!

DID YOU KNOW THERE ARE 10 EASY, FUN, AND CONVENIENT WAYS TO SUPPORT INDIVIDUALS AND FAMILIES LIVING WITH SPINA BIFIDA?

1. THE COLUMN: SBANENY’S MONTHLY GIVING SOCIETY
2. WALK-N-ROLL FOR SPINA BIFIDA
3. USE AMAZON SMILE WHEN YOU SHOP ONLINE
4. RECYCLE WITH SBANENY THROUGH CLYNK
5. PAYROLL GIVING
6. MATCHING GIFTS THROUGH YOUR EMPLOYER
7. SPONSOR A SBANENY PROGRAM OR EVENT
8. CELEBRATE YOUR BIRTHDAY WITH SBANENY ON FACEBOOK
9. DARE TO DREAM WITH SBANENY
10. DONATE AT WWW.SBANENY.ORG

Donate today or learn more about our 10 Ways of Giving by visiting www.sbaneny.org
SBANENY utilizes over 100 volunteers to establish the financial resources and in-kind support to provide programs and services to the estimated 10,000 individuals living with Spina Bifida in New York State.

<table>
<thead>
<tr>
<th>2020 Volunteer Hours</th>
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<tbody>
<tr>
<td>Committee Members</td>
</tr>
<tr>
<td>Student Interns</td>
</tr>
<tr>
<td>Remote Volunteers</td>
</tr>
<tr>
<td>Office Volunteers</td>
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</tbody>
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2020 Volunteer of the Year

Meghan Smith

Meghan began volunteering for SBANENY in 2018. Among a long list of enviable traits, Meghan stands out for her caring nature, light-heartedness, compassion for others, and willingness to help. Not only is she a wonderful person, but as a professional Meghan has an incredible work-ethic and commitment to our agency. In the office, Meghan takes on tasks eagerly, accepting any job that needs to be done and often stays until close. Meghan’s dedication to SBANENY is why she not only volunteers 3 to 4 times a week in the office but attends every SBANENY event she can and participates on the Walk-N-Roll committee. Because of this, Meghan has become someone the organization knows we can rely on to pursue our goals, and why she is the most deserving person to receive the inaugural SBANENY Volunteer of the Year Award!
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!