# A Year in Review

## ANNUAL OVERVIEW

<table>
<thead>
<tr>
<th>Count</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,750</td>
<td><strong>Requests for services</strong> responded to with support, information, and resources</td>
</tr>
<tr>
<td>21</td>
<td><strong>New families registered</strong> for services and receiving welcome packages</td>
</tr>
<tr>
<td>20</td>
<td><strong>Programs hosted</strong>, providing education and connections for people impacted by Spina Bifida</td>
</tr>
<tr>
<td>13</td>
<td><strong>Peer support groups</strong> hosted for adults living with Spina Bifida and caregivers of individuals living with Spina Bifida</td>
</tr>
<tr>
<td>8</td>
<td><strong>Scholarships awarded</strong>, increasing access to virtual opportunities through technology and students pursuing higher education</td>
</tr>
<tr>
<td>7</td>
<td><strong>Consumer Empowerment Stipends</strong> awarded to individuals impacted by Spina Bifida who co-facilitated chapter programs</td>
</tr>
<tr>
<td>3</td>
<td><strong>New hires</strong> including a part-time Case Manager and 2 interns living with Spina Bifida through the Employment Training Program</td>
</tr>
</tbody>
</table>
## Who we serve

- **61%**: Adults living with Spina Bifida/Caregivers of adults living with Spina Bifida
- **21%**: Caregivers of individuals living with Spina Bifida from 0-21 years old
- **18%**: Healthcare and service providers working with individuals and families impacted by Spina Bifida

## How we serve those impacted by Spina Bifida

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programming</td>
<td>38%</td>
</tr>
<tr>
<td>Information and Referrals</td>
<td>27%</td>
</tr>
<tr>
<td>Advocacy and Awareness</td>
<td>16%</td>
</tr>
<tr>
<td>Systems Navigation</td>
<td>12%</td>
</tr>
<tr>
<td>Support</td>
<td>7%</td>
</tr>
</tbody>
</table>

*Systems Navigation includes transportation, employment, benefits, education, housing, and healthcare.*
BRAND NEW VIRTUAL PROGRAMS

Program Title                                Attendance
Wellness Challenge                          50
Virtual Conference                          50
Skin Integrity Program                     60
Advocacy Series                            75
Paralympic Watch Parties                   160
Adaptive Fashion Show                      225

Wellness Challenge Testimony...
“This challenge has helped me a lot in many areas of my life. The program was great in so many ways; after recovering from a recent surgery, I needed to get back into certain healthy activities. The program offered a support community to stay motivated, bounce ideas off each other, and connect with others in the Spina Bifida community.”
- Heather Horwedel

Skin Integrity Series Testimony...
“Continue to provide programming that focuses on living healthy with Spina Bifida. The presentation was excellent - it focused on preventing pressure sores which are costly in terms of financial and also quality of life. Keep up the excellent work!”
- Anonymous

Virtual Programming Testimony...
“The programs are very enjoyable. Since I am on Long Island, as much as this pandemic has put me in QUARANTINE, I have never felt more part of a group since you have gone virtual.”
- Lisa Dennis
AWARENESS

The New York Mets recognized Spina Bifida and the Spina Bifida Association of Northeastern New York (SBANENY) on the field with the Team Spirit Award.

ADVOCACY

SBANENY advocates joined together to meet with 30 NYS representatives raising awareness about Spina Bifida and SBANENY services.

CLINICAL CARE

SBANENY’s Case Manager joined the team of providers meeting with patients at the pediatric and adult Spina Bifida clinics at Albany Medical Center Hospital.

SBANENY’s Executive Director, Julia Duff, received the Tom Baroch Advocacy award from the national Spina Bifida Association recognizing outstanding advocates on the national and/or state level!
### 2021 Financial Report

#### Balance – December 31, 2020

<table>
<thead>
<tr>
<th>Revenue</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>72,258</td>
</tr>
<tr>
<td>Donations</td>
<td>23,391</td>
</tr>
<tr>
<td>Grants</td>
<td>34,042</td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>9,916</td>
</tr>
<tr>
<td>Other Income</td>
<td>4,984</td>
</tr>
</tbody>
</table>

Total Revenue: **$144,591**

#### Expenses

<table>
<thead>
<tr>
<th>Expense</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programs</td>
<td>94,345</td>
</tr>
<tr>
<td>Fundraising</td>
<td>17,406</td>
</tr>
<tr>
<td>Administration</td>
<td>7,577</td>
</tr>
<tr>
<td>Insurance</td>
<td>4,206</td>
</tr>
<tr>
<td>Professional Fees - Accounting</td>
<td>2,100</td>
</tr>
<tr>
<td>Depreciation</td>
<td>0</td>
</tr>
</tbody>
</table>

Total Disbursements: **$125,634**

#### Investment Performance

<table>
<thead>
<tr>
<th>Performance Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gain (loss) from sale of investments</td>
<td>1,475</td>
</tr>
<tr>
<td>Unrealized gain (loss) on investments</td>
<td>10,790</td>
</tr>
</tbody>
</table>

Net Investment Gain (Loss): **$12,265**

#### Balance – December 31, 2021

Balance: **$198,784**
Volunteer of the Year
Mary Kate Sherlock

Eight years ago, Mary Kate began volunteering at the SBANENY office. Mary Kate is one of the most warm and considerate people we have come to know over the years. Each week, she enters the office with a smile and begins her day by checking in on each person working with her. In addition to volunteering at the office, Mary Kate assists with tabling at community events to provide education about Spina Bifida and SBANENY. She is also a regular attendee at advocacy meetings with Assembly Members and Senators, sharing her story about living with Spina Bifida. Mary Kate is a standout volunteer, always willing to learn new tasks and projects to give back to SBANENY. Thank you Mary Kate!
Growth Trends

**Programs & Services**
- Program opportunities increased by 74% from 2020 to 2021
- New consumer requests for services increased by 75% from 2020 to 2021

**Volunteers**
- Total volunteer hours increased by 150% from 2020 to 2021

**Revenue**
- Annual revenue increased by 58% from 2020 to 2021

**Personnel**
- To further enhance our services benefitting the Spina Bifida community, paid and volunteer personnel has more than doubled since 2019
How can you help us build a better and brighter future for all those impacted by Spina Bifida?

Give
- Donate
- Amazon Smile
- Recycling
- Round up your change
- Monthly donor
- Facebook

Join a committee
- Development
- Walk-N-Roll
- Dare to Dream
- Direct Mail Campaign

Volunteer
- Board of Directors
- Event planning
- Remote support
- Office administration

Sponsor
- Annual fundraiser
- Chapter program
- Awareness Month
- Walk-N-Roll
**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 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 before hiring their first part-time Executive Director in 2001. Twenty years later, the organization has grown, with one full-time staff, one part-time staff, and multiple interns now serving over 400 families, including adults with Spina Bifida, young children and their parents, siblings and service providers.

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**Staff: Julia Duff, LMSW**

**Executive Director**

**2021 Board of Directors**

- James Dunham, **Chair**
- Michelle Miller, **Chair Elect**
- Margaret Smith, **Immediate Past Chair**

- Dave Wentworth, **Treasurer**
- Jessica Ryder, **Secretary**

- James Alescio
- Chris Darby-King
- Robert Derrick
- Valerie Joseph
- Paul Lukasiewicz III
- Joe Slaninka
- Andrew White

**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!