



Liam Holleran
Journey Navy by Stride Rite



2021 Annual Report

Spina Bifida Association of Greater New England



Nyaja Childs
Manual Bag by PunkunFutz



50 Years Supporting the Spina Bifida Community

Letter from the Executive Director and Board Chair

Dear Friends,

Thank you for your continued interest and support of the Spina Bifida Association of Greater New England (SBAGNE). We are proud to celebrate 50 years of service to the Spina Bifida Community, and we could not have done it without you. You can find a commemorative 50th Anniversary video on our YouTube Channel (<https://www.youtube.com/watch?v=3uNXyPM-Ly&t=8s>).

Sadly, 2021 also marked the passing of our first Executive Director, Ellen Dugan. Ellen Dugan worked for SBAGNE for 12 years, and touched thousands of people with her compassion, humor, and support. We extend our deepest sympathies to Ellen's family, and are grateful, for the tremendous legacy she leaves with our organization. We are proud to announce our first Ellen Dugan Impact Award recipient, Dr. Lawrence Karlin, who has dedicated 40 years to supporting patients with Spina Bifida.

This annual report gives a snapshot of the challenging but exhilarating year we had in 2021, and highlights where and how our funds were used. We are especially proud to have been selected for a Spotlight Grant by the Christopher and Dana Reeve Foundation, and to have received declarations from the governors of all 6 New England states recognizing October as Spina Bifida Awareness Month.

The Board of Directors has been working hard to plan an even better year in 2022 for our Spina Bifida Community, including expanding and improving our existing programs as well as re-establishing our Regional Education Conference in November. We are Committed to providing diverse and inclusive programming to support our community.

We appreciate everything you do for SBAGNE, and want you to know how much your support means to our constituents. We are stronger together, and because of you we can SUPPORT, CONNECT, and EMPOWER individuals and families living with Spina Bifida All across New England. We look forward to being back together IN-PERSON in 2022!

Sincerely,

Amy Bois
Board Chair

Jean Bertschmann
Executive Director

SBAGNE Board of Directors

Executive Board

Amy Bois, Chair
Amie Richard, Vice Chair
Brendan Sullivan, Treasurer
John Wendell, Clerk

Board Members

Ashley Birch, Director
Jamie Curtis, Director
Lauren Dyer, Director
Enock Glidden, Director
Sarah Haywood, Director
Mary Holleran, Director
Linda Long-Bellil, Director
Jennifer Leidner, Director
Kristin Marquis, Director
Dr. Stuart Bauer, Director Emeritus



About SBAGNE

Mission

The mission of the Spina Bifida Association of Greater New England (SBAGNE) is to build a better and brighter future for all those impacted by spina bifida. We envision a world where everyone with Spina Bifida is accepted and thrives. Our tools are support, education, and advocacy.



About SBAGNE

History

Our organization was founded in 1971 by a group of parents of children with Spina Bifida as the Massachusetts Spina Bifida Association, Inc. Today, we cover most of New England and exist to enhance the lives of people living with Spina Bifida by building a strong community. We provide education and support to individuals as they move toward fulfilling and independent lives. Our vision is to promote access and change within society and respond to the needs of people of all ages living with Spina Bifida. SBAGNE currently employs a full-time Executive Director, part-time Operations Manager, part-time Accountant, and part-time IT Manager. The accomplishments and growth of SBAGNE are the direct result of the commitment, enthusiasm, and dedication of the Board, staff, and countless supporters.

In 2022, SBAGNE looks forward to reaching more individuals living with Spina Bifida, their families, caregivers, and supporters. The Spina Bifida Association of Greater New England is able to accomplish all that we do because of the donation of time and dollars from individuals like you.



Accomplishments

In 2021, SBAGNE intensified efforts to support individuals living with Spina Bifida, their families, friends, caregivers, and the professionals who work with them. In addition, SBAGNE also seeks to educate the public about Spina Bifida. During 2021, SBAGNE:

- Celebrated 50 years of service to the Spina Bifida Community;
- Awarded the first Ellen Dugan Impact Award to Dr. Lawrence Karlin, for his 40-year career supporting patients with Spina Bifida;
- Collaborated with collateral organizations and other interested partners to serve the needs of the Spina Bifida Community;
- Educated the public, physicians, and other health professionals about Spina Bifida;
- Operated support services to assist individuals with Spina Bifida, their families and caregivers;
- Advocated for public policies that increase government funding for Spina Bifida research, education programs, and support services;
- And received proclamations from the governors of all 6 New England states, declaring October as Spina Bifida Awareness Month.



Activities

In 2021, SBAGNE:

- Welcomed 25 families and 13 mentors to our Teen Empowerment Weekend for ages 11-18;
- Created a hybrid Walk-N-Roll and Summer Picnic with adaptive cycling, farm visits, caricature portraits, and photos with Elsa, which served 100 in-person attendees and a week of virtual resource-sharing from across New England;
- Provided our annual Jean Driscoll Scholarship to Julia Bellerose -- presented by Jean Driscoll herself!
- Held monthly virtual gatherings for adults living with Spina Bifida, as well as for teens;
- Hosted 177 guests at virtual and in-person Holiday Parties, with each guest receiving a curated gift;
- Collaborated with SBA of Northeastern New York on our 1st Annual Strut & Stroll Fashion Show, reaching 2,000 people;
- Collaborated with other SBA chapters to host virtual Paralympic Watch Parties for 160 people, spotlighting athletes with Spina Bifida;
- Provided over \$3,300 in Empowerment Grants to individual and families who requested assistance;
- Responded to more than 60 requests for information and referral;
- Fielded teams in the Falmouth Road Race and Tour de South Shore;
- Distributed Quarterly newsletters and monthly email updates to individuals, families, and professionals; and
- Produced a Virtual Conference/Speaker Series featuring representation from multiple clinics across New England during Spina Bifida Awareness Month; celebrating the 50th Anniversary of SBAGNE, and announcing the first annual Ellen Dugan Impact Award Winner.



Community Outreach

In 2021, SBAGNE increased its reach on social media: Facebook (1,483 followers), Twitter (637 followers), Instagram (644 followers). SBAGNE also increased its membership to 795 members: Maine (79 members/families), Vermont (8 members/families), New Hampshire (50 members/families), Massachusetts (492 members/families), Connecticut (65 members/families), Rhode Island (45 members/families).



Sponsors and Supporters

2021 Sponsors

Silver

Coloplast

Bronze

Boston Children's Hospital Pediatric Neurosurgery Foundation

Hollister

Massachusetts General Hospital for Children

MobilityWorks

Permobil

Friends of SBAGNE

Milford Federal Savings and Loan

National Seating and Mobility

2021 Grants

Christopher and Dana Reeve Foundation

Constance O. Putnam Foundation

The Lead Out Foundation

DCU for Kids Foundation

Ramlose Foundation

Matthew V. Joslin Fund

Walmart



Major Donors

\$5,000+

Richard Meelia
John & Amy Wendell

\$2,500 - \$4,999

Stephan & Emily Gagnon
Anne Wood

\$1,000 - \$2,499

Arbella Insurance Foundation
Sanford & Betsy Belden
Steve & Amy Bois
Darren Cartwright
Jack Connors
Dockendorf Family Trust
Kim Farrell
Christine Gilman
John McDonald
Nicole Sunderland
T-Stop Superette
Robert Weaver, Jr.
Renee Vrieze

\$500 - \$999

Bellerose Law Office, PC
Ginny Briggs & Matt Neal
Michael Conrad
Cynthia Fox
Roland Gagnon
Kerry Lesslauer
Linda Long-Bellil
Thomas Zug



Your Dollars at Work

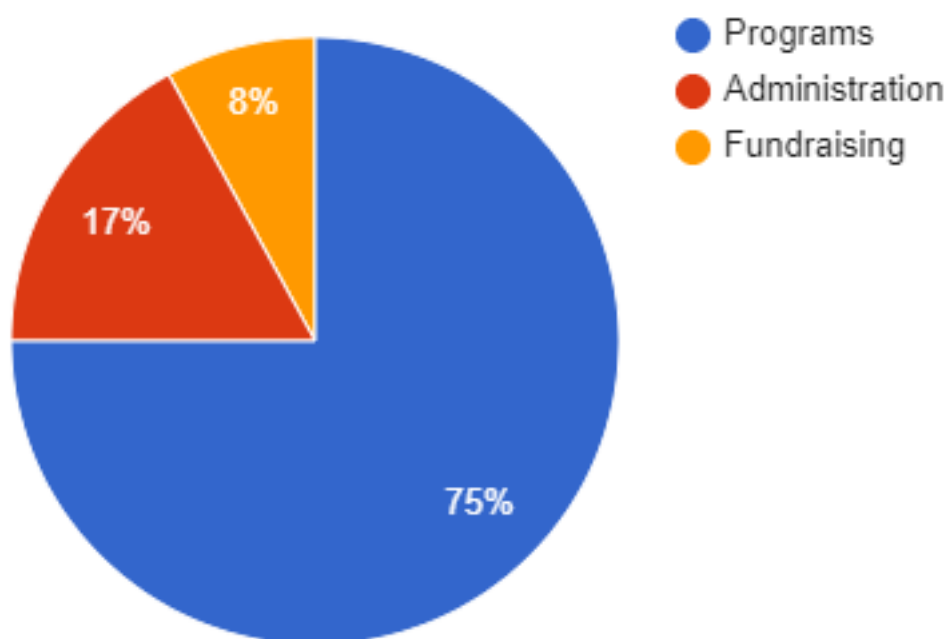
| 2021 Income: | |
|---------------------------|------------------|
| Fund Raising Events | \$105,457 |
| Grants and Contributions | \$123,147 |
| Miscellaneous | \$1,019 |
| Total | \$227,585 |
| 2021 Expenses: | |
| Event, Programs, Services | \$156,238 (72%) |
| Fundraising | \$24,921 (11%) |
| General/Administrative | \$36,035 (17%) |
| Total | \$217,194 |
| Total Assets: | |
| 2020 | 2021 |
| \$118,158 | \$133,508 |



2021 Expenses

- Total revenue 2021: \$225,839
- Total expense 2021: \$207,711
- Functional allocation of resources: 75% program; 17% administrative; 8% fundraising

Functional Allocation of Resources



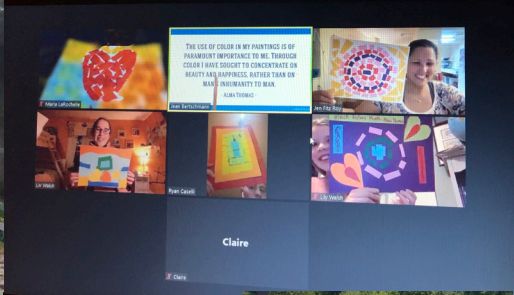
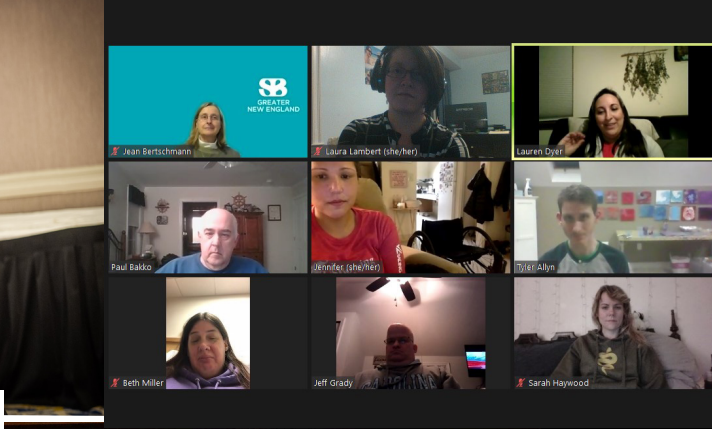
Spina Bifida Association of Greater New England
219 East Main St Suite 100 B, Milford, Ma 01757
www.sbagreaterne.org
Phone - 888-479-1900 Fax - 508-482-5301
EIN #: 23-7305430

The Spina Bifida Association of Greater New England is a registered 501(c)(3) organization.

The Spina Bifida Association of Greater New England is an affiliated chapter of the National Spina Bifida Association: <https://www.spinabifidaassociation.org/>

Donations are welcome and tax deductible.

SBAGNE is supported by generous individual donors, matching gifts, grants, and fundraising events.



Alternatives to Fusion

- Limited fusion (hemiepiphysiodesis)
- Delayed fusion (growing rods, VEPTR)
- Fusionless (stapling, ligament tethering)

