



Annual Report 2019

48 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 very proud of the work we have accomplished in the last year, and could not have done it without you. This Annual Report gives a snapshot of the amazing year we have just completed in 2019, and highlights where and how our funds were used. The Board of Directors has been working hard to plan an even better year for our Spina Bifida Community, including expanding and improving our existing programs as well as adding new programs in the coming months.

We appreciate everything you do for SBAGNE, and want you to know how much your support means to our constituents. We look forward to another successful year in 2020!

Sincerely,

Ginny Briggs

Board Chair

Jean Bertschmann

Executive Director

SBAGNE Executive Board

Ginny Briggs, Chair

Amy Bois, Vice Chair

Brendan Sullivan, Treasurer

John Wendell, Clerk

SBAGNE Board Members

Dr. Robert Burke, Director

Dan Holleran, Director

Linda Long-Bellil, Director

Jason Paynich, Director

Amie Richards, Director

Aimee Williamson, Director



Mission

The mission of the Spina Bifida Association of Greater New England (“SBAGNE”) is to promote the prevention of Spina Bifida and to enhance the lives of all affected. Our tools are support, education and advocacy.

History

Our organization was founded in 1971 by a group of parents of children with Spina Bifida as the Massachusetts Spina Bifida Association, Inc. Its original mission was: “Self-help and information decimation [sic] group for the betterment of birth-defect children and the family unit.” In 2006, the name was changed to Spina Bifida Association of Massachusetts, Inc.

In 1975, we joined the national Spina Bifida Association as an affiliated chapter. In 2011, we took on responsibility for Maine, New Hampshire, and Vermont. Today, we cover most of New England and exist to enhance the lives of people living with Spina Bifida by building a strong community of support. 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 the *SBAGNE* are the direct result of the commitment, enthusiasm and dedication of the Board, staff, and countless supporters.

In 2020, 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 2019, 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 2019, SBAGNE:

- Collaborated with collateral organizations and other interested partners to serve the needs of the Spina Bifida Community;
- Educated the public, physicians and other health professional 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.

ACTIVITIES

In 2019, SBAGNE:

- Hosted more than 200 attendees at the Maine and Massachusetts Walk n Roll/Family Picnics;
- Welcomed more than 20 participants at our BEST (Boys, Esteem, Success and Training) Meets BLIN'G (Better Living N' Girls) weekend for teens ages 11-18 and a parent;
- Held monthly gatherings for adults living with Spina Bifida;
- Hosted 200 guests at 2 Holiday Parties;
- Provided over \$1,500 in Empowerment Grants to individuals and families who requested assistance;
- Responded to more than 75 requests for information and referral;
- Provided outreach to 25,000 people at the Abilities Expo and Massachusetts Women's Conference;
- Created a national podcast providing information regarding Spina Bifida, SBAGNE, and the resources available through the National SBA;
- Fielded teams in the Falmouth Road Race and Tour de South Shore;
- Distributed Quarterly newsletters and monthly email updates to individuals, families and professionals;
- Featured multiple members via social media takeovers during Spina Bifida Awareness Month; and
- Increased our presence on social media with Facebook (1070 followers), Instagram (352 followers), and Twitter (604 followers).
- Reached 627 members! Massachusetts: 430; Maine: 58; New Hampshire: 32; Vermont: 8; Connecticut: 48; Rhode Island: 20; Misc.: 31



SPONSORS AND SUPPORTERS

2019 Sponsors

Gold

Arbella

Children's Hospital Orthopedic Foundation

Children's Hospital Pediatric Neurosurgery Foundation

Silver

Hollister;

Pediatric Associates of Lewiston

Bronze

Wellspect

Milford Federal

Friends of SBAGNE

Kennebec Pharmacy

2019 Grants

Constance O. Putnam Foundation

Dunkin Donuts Joy in Childhood Foundation

DCU for Kids Foundation

Blue Cross/Blue Shield

Matthew V. Joslin Fund



Circle of Strength Donors

Circle of Aspirations - \$ 5000- \$9999

Richard Meelia
John and Amy Wendell
Dockendorf Family Trust

Circle of Opportunity - \$2500 – \$4999

Steven and Amy Bois
Emily and Stephan Gagnon

Circle of Possibility - \$ 1000- \$2499

Nicole Sunderland
John Connors
Marc Conroy
Susan Drake

Mary Dunbrack
Kevin and Mary Ellen Kelley
Kerry Lesslauer
Robert Weaver, Jr.

Circle of Promise - \$ 500-\$999

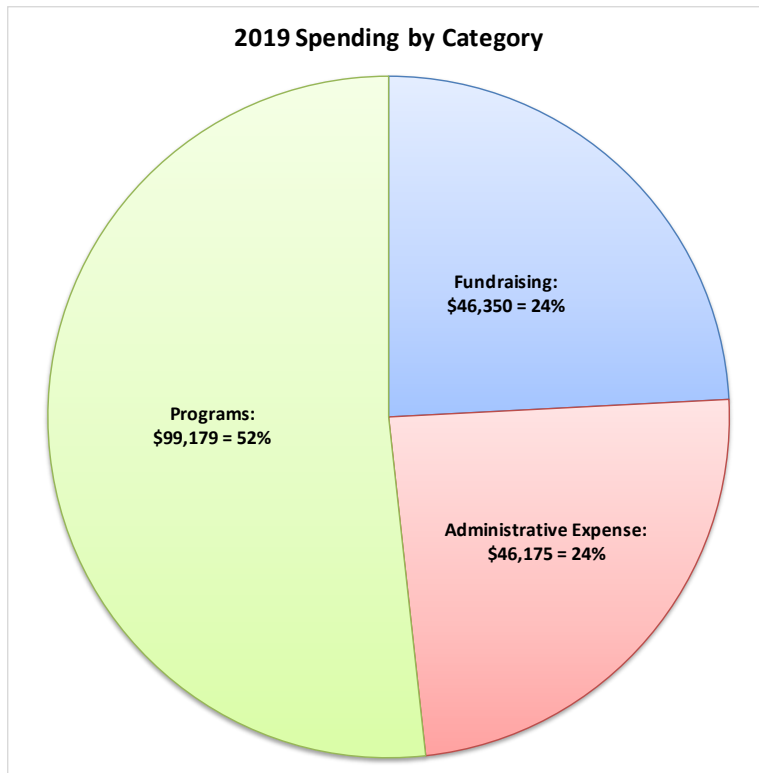
Cathy Angell
Jose Almeida
Nimesh Bhagat
Patrick Brannigan
Catherine Cooke
Brian Davidson
Kevin and Kathy Dougherty
John Dias
Catherine Dito

Christine Gilman
Brenda Henry
Craig Hindman
Kirk and Sheila Joslin
Christopher and Marcia
Klapper
Anthony J. Leo
Linda Long-Bellil
Deb McNamara

Dr. Julie Nash
Terry Malick
John Masterson
John McDonald
Chip and Robin O'Neill
Evelyn Packard
Edwin Pease
Paul Pressler
Lindsey Resto

YOUR DOLLARS AT WORK

2019 Income:	
Fund Raising Events	\$148,382
Individual and Corporate Contributions	\$29,872
Grants	\$44,000
Miscellaneous	\$3,414
Total	\$225,668
2019 Expenses:	
Event, Programs, Services	\$147,220
General/Administrative	\$46,175
Total	\$193,395
Total Assets:	
2018	2019
\$93,451	\$127,626



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.