

SPINA BIFIDA ASSOCIATION
OF GREATER NEW ENGLAND

ANNUAL REPORT

2022



51 years of supporting
people living with
Spina Bifida

Letter from the Board Chair and Executive Director

Dear Friends,

Thank you for your continued interest and support of the Spina Bifida Association of Greater New England (SBAGNE). We are very proud to celebrate 51 years of service to the Spina Bifida community, and we could not have done it without you.

This Annual Report gives a snapshot of the exhilarating year we had in 2022 with a return to in-person programming, and highlights where and how our funds were used. We are especially proud to have renegotiated our service area with the National Spina Bifida Association, to officially include Connecticut and Rhode Island in our Chapter. We have long been serving these communities, and are grateful for the endorsement of those efforts by our national partners.

Looking ahead, the Board of Directors has been working hard to plan an even better year in 2023 for our Spina Bifida community, including the addition of an Adult Empowerment Program, and Family Camp Weekend, and programming specifically tailored to our families for whom Spanish or Portuguese are their primary language. We are committed to providing diverse and inclusive programming to support our entire 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.

Sincerely,

Amie Richards
Board Chair

Jean Bertschmann
Executive Director

SBAGNE Executive Board

Amie Richards, Chair
Linda Long-Bellil, Vice Chair
Brendan Sullivan, Treasurer
Jamie Curtis, Clerk
Amy Bois, Immediate Past Chair

SBAGNE Board Members

Ashley Birch, Director
Mary Holleran, Director
Jennifer Leidner, Director
Nathan Bellerose, Director
Tom Bodden, Director
Steve Hornsby, Director
Andrew White, Director
Lena Williamson, Director
Dr. Stuart Bauer, Director Emeritus

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.

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 donors and volunteers.

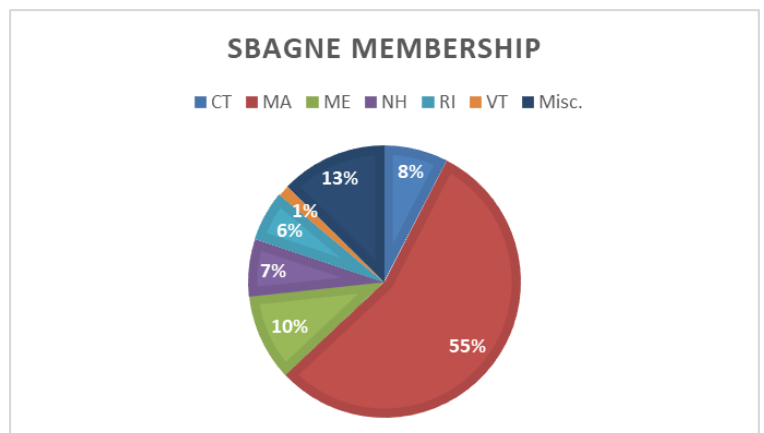
In 2022, SBAGNE was able to reach more individuals living with Spina Bifida, their families, caregivers and supporters. SBAGNE is able to accomplish all that we do because of the donation of time and dollars from individuals like you.

Accomplishments

- Celebrated 51 years of service to the Spina Bifida community;
- Awarded the second Ellen Dugan Impact Awards to Rebecca Sherlock, MSN, RN, PPCNP-BC, and Mary Jo Dunleavy, RN for their tremendous work coordinating the Spina Bifida Clinic at Boston Children's Hospital, and for supporting patients with Spina Bifida;
- Presented at the National Clinical Care Conference at Boston Children's Hospital;
- Hosted a Regional Education Conference which educated the public, physicians and other health professional about Spina Bifida;
- Presented at the New England Regional Genetics Group Annual Conference;
- Provided support services to assist individuals with Spina Bifida, their families and caregivers;
- Initiated a quarterly meeting for clinical staff at all 9 New England pediatric Spina Bifida clinics;
- Advocated for public policies that increase government funding for Spina Bifida research, education programs, and support services;
- Received 4 Chapter Awards from the National Spina Bifida Association; and
- Received proclamations from Governors of all 6 New England states declaring October as Spina Bifida Awareness Month.

Activities

- Supported national advocacy efforts at a virtual Teal on the Hill;
- Held monthly virtual gatherings for adults living with Spina Bifida, as well as for teens including virtual escape rooms, Family Game Night, and Virtual Valentines;
- Distributed Quarterly newsletters and monthly email updates to individuals, families and professionals;
- Welcomed 35 families and 15 mentors to our Teen Empowerment weekend for teens grades 6 – 12;
- Collaborated with SBA of New York State on our 2nd Annual Strut and Stroll Fashion Show, reaching 1,000 people;
- Volunteered at the Boston Marathon to support wheelchair and adaptive athletes;
- Provided our annual Jean Driscoll Scholarships to Thalia Almeida and Jordynne McKinstry – presented by Jean Driscoll herself!
- Returned to in-person Walk-N-Roll/Summer Picnics with adaptive sports, farm visits, and a beach outing for 225 people;
- Presented about chapter-clinic collaborations at the Spina Bifida Clinical Care Conference at Boston Children's Hospital;
- Established new regional Meet Your Neighbor events, including baseball games, hikes, and a day at the racetrack;
- Collaborated with other SBA chapters to host virtual Paralympic Watch Parties, a virtual 100 Mile Challenge Wellness Program, and launch a virtual Book Club;
- Fielded teams in the Falmouth Road Race and Tour de South Shore;
- Presented to genetics students at Brandeis, Mass General, Boston University and the New England Regional Genetics Group;
- Presented a Regional Education Conference, highlighting Jean Driscoll as the Keynote Speaker.
- Hosted 160 guests at in-person Holiday Parties, with each guest receiving a curated gift;
- Provided over \$6,300 in Empowerment Grants to 30 individuals and families who requested assistance;
- Responded to more than 90 direct requests for information and referral from members in all 6 New England States;
- Increased our presence on social media with Facebook (1,700 followers), Instagram (1,102 followers), and Twitter (614 followers); and
- Reached 1,273 members! Massachusetts: 706; Maine: 131; New Hampshire: 87; Vermont:17; Connecticut: 96; Rhode Island: 75; Misc.: 161





SPONSORS AND GRANTORS

2022 Sponsors

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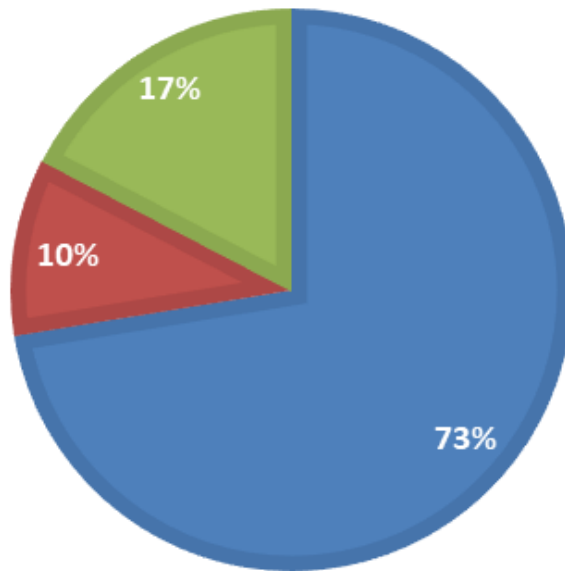
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Kayleigh O'Brien
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T-Stop Superette
John Walsh
Andrew White

YOUR DOLLARS AT WORK

	2022 INCOME	
Fundraising Events	\$ 108,823	53%
Grants and Contributions	\$ 94,238	46%
Miscellaneous	\$ 1,447	1%
TOTAL	\$204,508	100%
	2022 EXPENSE	
Event, Programs, Services	\$ 191,936	73%
Fundraising	\$ 26,987	10%
General/Administrative	\$ 46,131	17%
Total	\$265,054	100%
	TOTAL ASSETS	
2020	2021	2022
\$118,158	\$133,508	\$ 104,984

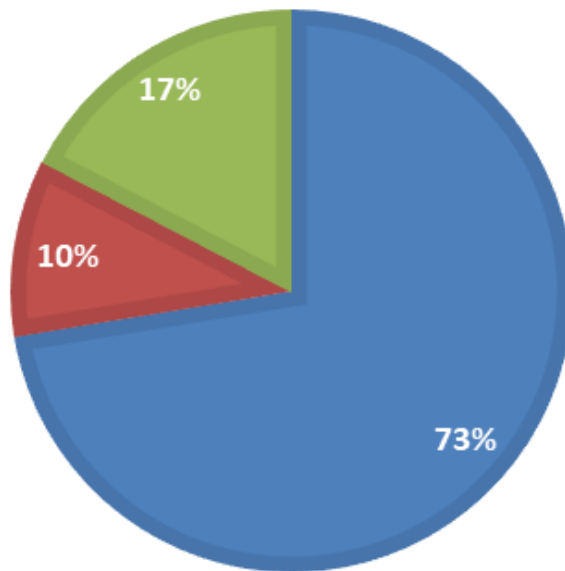
SBAGNE 2022 REVENUE

■ Event, Programs, Services ■ Fundraising ■ General/Administrative ■



SBAGNE 2022 EXPENSES

■ Event, Programs, Services ■ Fundraising ■ General/Administrative



IN MEMORY OF:

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Dianne Doyle

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Nedda Hobbs

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MARTIN LEBLANC

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Shannon LeBlanc

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TOM PALMER

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Brooke Joiner

Charles Pagliazzo

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Linda Rice

Anne Smolen

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SARAH EMILY SHOREY

Thomas P. Shea

GAY TURINI

William and Joan Gay

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Sue FitzPatrick

WILLIAM WARD

Carvalho/Morton Families

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Carole & J.J. White

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Edwin Kinnen

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James Burns

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Carmine and Mary Ann Parlapiano
Sue Fitzgerald and Lee Peters
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Michael and Ranette Moore
Eileen Ratcliffe
Maureen Reda
Eleanor Terry

SEAN FARRELL

Judith Kelly
Kathleen and Dennis Marvelle



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Olga LeBron-Sanchez

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Anne Wood

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Joseph and Mary Sciuto

JACK PAYNICH

Bonnie Paynich

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Karen and Ronald Vrieze

CALEB WONG

Soothing Way, LLC







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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.

Donations are welcome and tax deductible.

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