2020 Annual Report

Spina Bifida Association of Greater New England

49 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 challenging year we all experienced in 2020, and highlights where and how our funds were used. The Board of Directors has been working hard to plan an even better year in 2021 for our Spina Bifida Community, including expanding and improving our existing programs as well as adding new programs in the coming months. We are committed to providing diverse and inclusive programming to support our community.

We appreciate everthing 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 our individuals and families living with spina bifida all across New England. We look forward to being back together IN PERSON in 2021!

Sincerely,

Amy Bois	**Jean Bertschmann**
Board Chair	Executive Director

SBAGNE Board of Directors

Executive Board

Amy Bois, Chair
Jason Paynich, Vice Chair
Brendan Sullivan, Treasurer
John Wendell, Clerk
Ginny Briggs, Immediate Past Chair

Board Members

Ashley Birch, Director
Dr. Robert Burke, Director
Sarah Haywood, Director
Dan Holleran, Director
Linda Long-Bellil, Director
Kristin Marquis, Director
Amie Richards, 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. 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 accomplishements and growth of SBAGNE are the direct result of the commitment, enthusiasm, and dedication of the Board, staff, and countless supporters.

In 2021, SBAGNE looks forward to reaching more individuals living with spina bifida, their families, caregivers, and supporters. The Spina Bifida Association of Greater New Englandis able to accomplish alll that we do because of the donation of time and dollars from individuals like you.

Accomplishments

In 2020, 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 publish about spina bifida. During 2020, 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 professionals about spina bifida;
- Operated support services to assist individuals living 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 a proclamation from Governor Baker, declaring october as Spina Bifida Awareness Month in the Commonwealth of Massachusetts.

Activities

In 2020, SBAGNE:

- Welcomed more than 30 families to our BLING Meets BEST empowerment weekend for teens and tweens ages 11-18 and a parent;
- Posted daily COVID-19 resources and medical supplies to our social media;
- Created a Virtual Walk-N-Roll and Summer Picnic with 4 days of events, resources, and activities;
- Provided 4 Jean Driscoll Scholarships to teens -- presented by Jean Driscoll herself!
- Held monthly virtual gatherings for adults living with spina bifida, as well as for teens;
- Hosted 200 guests at a virtual Holiday Party with each guest receiving a curated gift box;
- Provided over $2,750 in Empowerment Grants to individuals and families who requested assistance;
- Responded to more than 60 requests for information and referral;
- Created a national podcast providing information regarding spina bifida, SBAGNE, and impact of COVID-19;
- Fielded teams in the virtual Falmouth Road Race and virtual Tour de South Shore;
- Distributed quarterly newsletters and monthly email updates to individuals, families, and professionals; and
- Featured a Speaker Series with representation from multiple clinics across New England during Spina Bifida Awareness Month.

Community Outreach

In 2020, SBAGNE increased its reach on social media: Facebook (1,102 followers), Twitter (629 followers), Instagram (441 followers). SBAGNE also increased its membership to 707 members: Maine (69 members/families), Vermont (8 members/families), New Hampshire (44 members/families), Massachusetts (458 members/families), Connecticut (61 members/families), Rhode Island (35 members/families).

Sponsors and Supporters

2020 Sponsors

Bronze

180 Medical
Boston Children's Hospital Pediatric Neurosurgery Foundation
Coloplast
Hollister

Friends of SBAGNE

Boston Children's Hospital Urological Foundation
Milford Federal Savings and Loan

2020 Grants

Constance O. Putnam Foundation
Integra Life Sciences
Ramlose Foundation
Matthew V. Joslin Fund

Major Donors

$5,000+

John and Amy Wendell
Richard Meelia
Dockendorf Family Trust

$1,000 - $2,499

Nancy Testa
Rebecca and Jason Paynich
Renee Vrieze
Derek Vrieze
Kristin and Jose Almeida
Mary Dunbrack
Jerilyn Asher Shepard

$2,500 - $4,999

Michael Sliney
Emily Gagnon

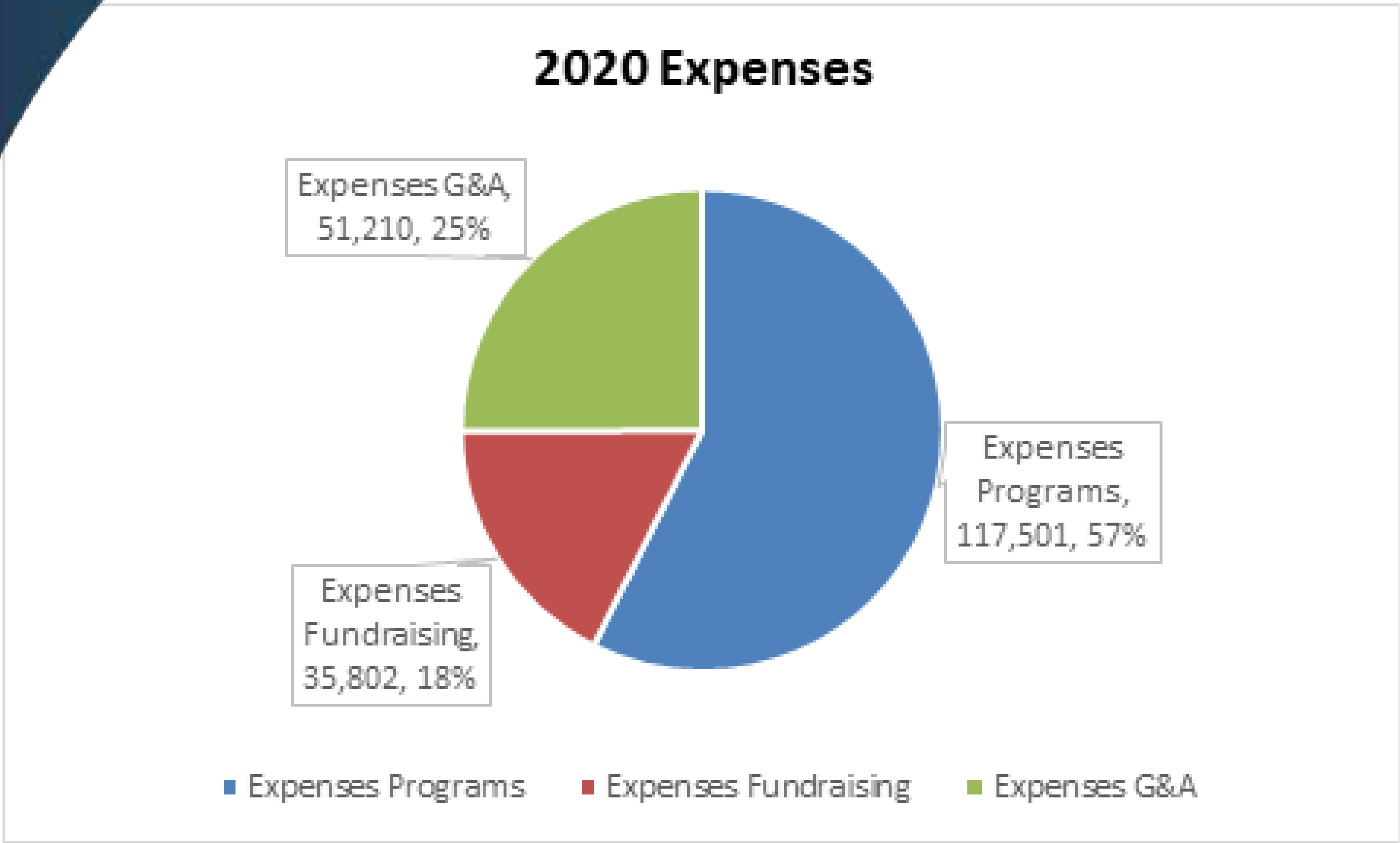
$500 - $999

Steve and Amy Bois
Anthony J. Leo
Nicole Sunderland
Elizabeth Diron
Rebecca Sherlock
Nedda Hobbs
Sally and Daniel Joyce
Roland Gagnon
Debra and Ed McNamara
Robert and Lis Donnelly
Kerry Lesslauer
Kathleen Karpe

Your Dollars at Work

2020 Income:	
Fund Raising Events	$98,404
dividual and Corporate Contributions	$37,527
Grants	$31,000
Miscellaneous	$13,047
Total	$179,978
2020 Expenses:	
Event, Programs, Services	117,501
Fundraising	35,802
General/Administrative	51,210
Total	204,513
Total Assets:	
2019	2020
$127,626	$118,158

2020 Expenses



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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: https://www.spinabifidaassociation.org/
Donations are welcome and tax deductible.
SBAGNE is supported by generous individual donors, matching gifts, grants, and fundraising events.


WE LOVE YOU
Brianna
SPINA BIFIDA
SPINA BIFIDA STRONG
We are
SPINA BIFIDA STRONG
Caselli
Beth Miller
Grace Briggs-Noel