

Fall/Winter 2020

SB SBAGNE

news

The SBAGNE Holiday Party Goes Virtual

Serving you in new ways and unusual circumstances



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SBAGNE is a group of parents, adults and children with spina bifida and dedicated professionals working together to support and encourage families and individuals throughout the Greater New England area. It is our goal to enrich the lives of those affected by spina bifida through education, parental support, social networking, advocacy, and public awareness.

Consider helping SBAGNE meet its goals with a personal or matching donation. Visit SBAGreaterNE.org today to contribute.

A Special Hello from our Board Chair

Hello SBAGNE Family,

I wish you all a Happy and Safe Holidays and I looking forward to later in 2021 when we call all be together again in-person. Until then I invite you to join us in our wide range of virtual programs and activities we have planned for the first half of the year.

We are also excited to have launched our campaign, “Shopping for a Cause” this past year. Through this program, we have been able to connect you with valuable adaptive resources, offer discounts, and raise funds for other SBAGNE programs and events. We have partnered with such brands as Billy Footwear, UniteAble, IZ Adaptive, and Bold Body who offer adaptive and universally designed clothing and footwear. You are able to purchase discounted products through our relationships with these designers and a portion of their proceeds also go back to SBAGNE to support community activities. We have also run fundraisers with One Hope Wine and Rebecca’s Nut Free Cookie Dough as a fun way to get into the holiday spirit this season. You can still purchase wine from One Hope using our fundraising link: <https://www.onehopewine.com/event/70667>

In 2020 we had two Board Members fulfill their terms. Thank you to Ginny Briggs and Dan Holleran who completed 13 and 3 years of service respectively. Best wishes to you both.

We extend a big welcome to our new Board Members joining us in 2021: Enock Glidden, Mary Holleran, Jennifer Leidner, Lauren Dyer, and Jamie Curtis. We are excited to work with you all.

Once again, I wish you the best this holiday season and cannot wait to connect with you again in the new year!

-- Amy Bois



2021 Calendar

In light of the COVID-19 pandemic and news of recently approved vaccines, we expect to reintroduce in-person programs and events in the second half of 2021. We will operate within the public health advisories from local, state, and national leaders.

- January 11 - March 29: Lead the Way Adult Leadership Program (Virtual)
- February 14 - March 17: Wellness Challenge (Virtual)
- February 14: Valentine's Parties (Virtual)
- March (TBD): Adaptive Fashion Show (Virtual)
- March 1-5: Teal on the Hill (Virtual)
- May (TBD): Meet Your Neighbors (Location TBD)
- June 4-5: National Clinical Care Meeting (Virtual)
- July 17: Browne Center (Durham, NH)
- August 22: Falmouth Road Race (Falmouth, MA)
- August 27-29: BEST Meets BLIN'G (Nashua, NH)
- September (TBD): Meet Your Neighbors (TBD)
- September 18: Tour de South Shore (Hingham, MA)
- October 3: Maine Marathon (Portland, ME)
- October 22-24: Regional Conference/50th Anniversary Celebration (Nashua, NH)
- October 1-31: Spina Bifida Awareness Month
- World Spina Bifida Day
- November (TBD): Meet Your Neighbors (TBD)
- December 4: Maine Holiday Party (TBD)
- December 5: Massachusetts Holiday Party (Weston, MA)

Ongoing:

- Adult Group Virtual Happy Hours (contact llambert@sbagreaterne.org for more)
- Quaran-teens Virtual Hangouts (contact jbertschmann@sbagreterne.org for more)

To Be Determined:

- Monthly Webinars
- Adult Group Virtual Valentine's Day
- Massachusetts Walk-N-Roll/Summer Picnic (projected for June)
- Piers Point Adaptive Sailing (projected for June)
- Maine Walk-N-Roll/Summer Picnic (projected for August)
- Comedy Night (projected for September/October)

Memorial Donations and Honorariums

We recognize the following people for donating to SBAGNE in memory or honor of a loved one in 2020. We appreciate your thoughtful generosity and extend our warmest wishes to you and your family.

In Honor of Emily Lane

Catherine Nicastro
Theresa Lane

In Honor of Sarah Rafala

Barbar Bo Rockwell

In Honor of Patricia Forlizzi

Carol Passacantilli

In Memory of Jean Ferraro

Robert Bazinet
Jean Ellen Keras

In Honor of Kristin Marquis

Madeleine's Daughter Bridal

In Memory of Nicole Bongiolatti

Lee and Cathy Bongiolatti

In Memory of Dennis Quigley

Genevieve Bulmer
Mr. & Mrs. Clarence Hannan
Marie Hayes

In Memory of Josephine Henderson

Carol Passacantilli

In Memory of Eileen O'Mally

Norwood Garage Local 2222

In Memory of Gary Lewis

Rich Robinson
Ronald & Patricia Stachowski
Laureen Florio
Mary Ellen Lewis

In Honor of Tyler Bois

Robert and Shelly Bois

In Memory of Charles L. Burke, Jr.

Nicole DiSpena

In Memory of Wilma Cosgrove

Rebecca Sherlock

In Honor of Helena Fontaine

Richard & Paula Gravina

In Honor of Jacob Fowler

Brian & Gail Cassidy

In Honor of Corey Wemple

Melody & James Buckley

In Memory of Jennifer Posnik

Jerilyn Asher & Craig Shepard

In Memory of J. David Hobbs

Rose-Marie
Nedda Hobbs
Michelle Baum
Donnamarie Kifer
Deborah Ashjian
Children's Hospital Spina Bifida Clinic
Elizabeth Gould

In Memory of Patrick B. Sullivan

Jay & Lenore Connelly
John Edwards
Joseph Connelly
Monica Nakielski
Nancy Burns
Judith A. Castricone
Mr. & Mrs. Joseph Connelly
Dianne MacFarland
Mary Harrington &
Walter Landergan
Sheila Anne Harrington
Joan Sullivan
Margaret MacFarland
Peter E. Neitz
James & Jennifer Walker
John & Heather Welch

In Memory of Rose Frances Miller

Andrew Racca
Susan Pereira
Jessica Howell

In Honor of Ryan Caselli

Ryan and Angela Saul

In Honor of Cynthia Donovan

Francis Sampson

In Honor of Sarah Shorey

Colleen Murphy

In Memory of Josephine Henderson

Carol Passacantilli

In Memory of Matthew V. Joslin

Kirk & Sheila Joslin

In Honor of the Gagnon Family

Paul Newman

In Honor of Lena Williamson

Arlene Vezina

In Honor of Jack Paynich

Bonnie Paynich

In Memory of Mark Reed

Carol Passacantilli

In Honor of Brayden Langlais

Patricia and Allan Jandreau

In Honor of Liam Milnes

Joseph and Mary Anne Sciuto

In Honor of Katie Packard

Paul and Adele Maguire

In Honor of Lilyan Vandevender

Gary Rybicki

In Honor of Anne & David Lane

Doris & Joe Amaral

In Memory of Mary McDonald

Kevin Ahl
Janet & Peter Sennott
Kathleen Fallon
John, Stephen, Courtney Fallon & Arnette
Chang
Patricia Fallaon and Gerald Demko
Charles River Country Club
Mike & Mary Pay Cunniffe
Karen & Glen Anderson
Anne, John, & Thomas Weiss
Peggy Noonan
Sheila Farley
Kevin & Kathleen McSheffrey
Peggy Riley
Philip & MaryAnn Larocque

In Memory of Patricia Burke

Erin & Jim Christino
Jim & Erica Sanzi
Hope & Gary Bazer
Kevin Burke
Diame Allmandinger
Anne McAuliffe-O'Donnell
Kathleen Mcardle
Sharon Deroeck/Meryt Almmendinger
Margaret & Charles Papini
Sally & Daniel Joyce
Alanna Burke
Chris & Jean Bertschmann
Jean Lorence
Kirk & Sheila Joslin
Wayne Kezirian & Betsy Paroli
Richard & Linda Rosholt
Arlene & Neal Rogol
Rebecca Sherlock
Scott Rice
Ellen Amore
David & Gale Swenson

In Honor of Cynthia Donnelly

Jen Pouche-Mc-Devitt

From the Desk of the Executive Director

Dear SBAGNE Family,

What a difference a year makes! The COVID pandemic has lasted so much longer than we ever anticipated, and has certainly taken a toll on our community. I hope this finds you and your families staying physically and emotionally healthy and well. This is such a strong community and I am sure we are all celebrating that there is now a light at the end of the tunnel.

The New Year always brings with it a chance for reflection and re-commitment. Despite the challenges of 2020, there were so many highlights! Laura and I worked hard to continue our connections with all of you in a virtual world, and we are so grateful for your engagement. We had more than 500 people participate in virtual programming including our weekly hangout groups, our Virtual Walk-N-Roll/Summer Picnic, our October Speaker Series, and our year-end virtual Holiday Party with almost 200 guests! We were especially proud to receive a proclamation from Governor Baker designating October as Spina Bifida Awareness Month in Massachusetts, and look forward to expanding this recognition to our other states in 2021.



Looking ahead, 2021 is chock-full of promise! Of course, the promise of the vaccines to facilitate a person to in-person programming is a huge cause for celebration. We hope to return to live events in the second half of the year, but are enjoying the opportunities that the virtual world offers to us in the meantime. We are excited about several new programs: a leadership development program for our adults, virtual valentine parties for all age groups, a fashion show featuring adaptive clothing and footwear designers and our own models, and a month-long wellness challenge to help us all re-commit to a daily focus on our physical, nutritional, and mental health. We have also added some fun, new live programs to help deepen connections across the community. We will start a series of Meet Your Neighbor regional dinner parties, enter a new team in the Maine Martahon, and we WILL have our Conference and 50th Anniversary party in October.

Please join me in thanking the SBAGNE Board for their hard work in a particularly challenging year financially as well as logistically. Their engagement and guidance were critical throughout the year. Our deepest gratitude to Ginny Briggs and Dan Holleran, who are both retiring from the Board in 2020. Their commitment and contributions are immeasurable, and we know they will continue to be active members of the organization.

Cheers to a happy and healthy New Year filled with new friendships, new goals, and new celebrations!

-- Jean Bertschmann

Fundraising and Awareness



Over the last several months, we have found new and exciting ways to raise both funds and awareness for the spina bifida community in the virtual landscape. Thank you to everyone who participated in one of the fundraisers below and remember, every time you make a donation ask, you are also opening a door for awareness and education by sharing SBAGNE's mission and community with your donor.



Our New Balance Falmouth Road Race team raced virtually this year. They were some of the top fundraisers for the non-profit teams in this year's race and raised \$47,687 in support of SBAGNE's programs and community events.



Our Tour de South Shore team raced virtually this past September. They raised \$16,630 in support of SBAGNE's programs and community events. Thank you to the Holleran Family for leading our team and building our connection to the McCourt Foundation!



We participated in HundredX Express Feedback for Good program this past October. By providing market feedback, our members were able to generate income for SBAGNE without making a personal donation.



In preparation for the holiday season, we partnered with Rebecca's Nut Free to bring families tasty and allergy-free cookie dough. We raised \$546 through this fun fundraiser!



Our annual appeal began in October in conjunction with Spina Bifida Awareness Month. If you would like to make a donation, you can do so by visiting <https://www.sbagreaterne.org>.



We are running a fundraiser with One Hope Wine. If you would like to stock your wine rack or give a gift this season, you can make your purchase support SBAGNE at <https://www.onehopewine.com/event/70667>



Our Recent Programs

Over the course of 2020, we have found new and exciting ways to offer virtual programs to members across New England. Our programs included webinars, virtual hangouts, Sketch and Sip Night, Rising Phoenix Watch Party, and Holiday in a Box Virtual Party.



Visit our YouTube Channel (Spina Bifida Association of Greater New England) to watch our growing collection of webinars. If you would like to participate in one of our virtual hangouts, contact Laura Lambert at llambert@sbageaterne.org. Keep an eye on our website and social media for information about new and upcoming events and programs for 2021!

Upcoming Programs



Join us for new and annual programming in 2021! We look forward to offering both virtual and in-person activities as public health needs allow. Join us for events like a virtual Fashion Show and Valentine's Parties, BEST Meets BLING, and more!



Early in 2021, we will (virtually) offer a leadership program for adults with spina bifida, a Wellness Challenge, Valentine's Parties, and an Adaptive Fashion Show. Our BEST Meets BLING program, traditionally held in March has been rescheduled for August 27-29 so that this program can take place in person!

Our Appreciation

2020 Sponsors & Grantors

Constance O. Putnam Foundation
Boston Children's Pediatric
Neurosurgical Foundation
Boston Children's Urological Foundation
180 Medical
Hollister
Coloplast
Integra Life Sciences
Milford Federal Bank
Ramlose Foundation

3rd Party Fundraisers

Express Feedback for Good
Rebecca's Nut Free Cookie Dough
One Hope Wine
BILLY Footwear
Bonfire SWAG
Stop & Shop Bags 4 My Cause
Chrome Angelz: Misfitz & Heathenz Chapter

Amy Bois (Facebook Fundraiser)
Amie Richards (Facebook Fundraiser)
Sarah Scott (Facebook Fundraiser)
Dee Sullivan (Facebook Fundraiser)
Jessica Guest (Facebook Fundraiser)
Teena Rose Lessard French (Facebook Fundraiser)
Amy O'Brien (Facebook Fundraiser)
Lauren Dyer (Facebook Fundraiser)
Hailey Fish (Facebook Fundraiser)
Lisa Ann (Facebook Fundraiser)
Colette Bither (Facebook Fundraiser)
Xaimara Angel Xiolana Xax (Facebook Fundraiser)
Katie O'Leary (Facebook Fundraiser)
Sarah Rafala (Facebook Fundraiser)
Maria Jimenez (Facebook Fundraiser)
Michelle Marotz (Facebook Fundraiser)
Kristin Lovering Marquis (Facebook Fundraiser)

You can be a 3rd party fundraiser too! It can be as simple as starting a **Facebook fundraiser**. Contact llambert@sbageaterne.org for more information on how to become a 3rd party fund-raiser.

2020 Volunteers

We would like to thank everyone who helped organize this year's activities. Your involvement helped make it possible to bring people together, celebrate our community, raise awareness, and host programs and events for the Spina Bifida Community! Anyone interested in volunteering for one of our upcoming programs or becoming part of a planning committee should contact Jean Bertschmann at jbertschmann@SBAGreaterNE.org.

Annual Appeal

Our annual appeal is coming to a close. We welcome any last minute donations and express our thanks to everyone who donated during this unique and difficult year. Your support enables us to continue to adapt to a changing environment and offer new and improved virtual and in-person programs in 2021.

Our vision is to build connections and community, break down barriers, promote access and change within society, provide education, and support individuals as they move toward fulfilling and independent lives.

Donate today at <https://sbageaterne.org/get-involved/make-a-donation/>.

Programs and Resources

SBAGNE Empowerment Program

The Empowerment benefit may be used for reimbursement for adaptive equipment, camps, adaptive sports and recreation, urological supplies for individuals older than three, durable medical equipment, and assistive technology.

This \$250 benefit is available to all SBAGNE members living with spina bifida (a parent or guardian may apply on behalf of children under 18). Applications are accepted on a rolling basis and Empowerment benefits are awarded monthly.

Visit www.SBAGreaterNE.org for more information or to apply.

Public Transit Sticker

The Transit Supply online store offers a wide range of transportation related pins, stickers, and magnets, including a disability-specific transit card sticker. This sticker includes the phrase “Please offer me a seat. Not all disabilities are visible.” If you use public transportation and would like to make use of this sticker, visit the Transit Supply online store at <https://transit.supply/search?q=disability>.



Supply Distribution

A member of the SBAGNE community has donated a Bella's Bumba, prone stander, and rolling stander. If you are in need of one of these devices, please contact jbertschmann@sbagreaterne.org.

Because of the disruptions to supply chains, we have expanded our collection of catheter supplies. If you are interested in receiving any, please contact our office at 888-479-1900 or jbertschmann@sbagreaterne.org for more details or to arrange pick-up. A full list of available supplies is available at <https://sbagreaterne.org/>.

Spina Bifida Association App

The national Spina Bifida Association has released an app containing the fourth edition of the “Guidelines for the Care of People with Spina Bifida.” This resource discusses care at various stages of life and can be put to personal use or shared with medical professionals to improve conversations between you and your doctor. This app is available for download through your app store under the name “Spina Bifida Association.”

Interviews with Athletes

SBAGNE members, Amy and Tyler Bois, recently had the opportunity to interview athletes with spina bifida. We invite you to watch them at the links below.

[Interview with Daniel Romanchuk](#)
[Interview with Enock Glidden](#)

Contacts

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Adult Group

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Walk-N-Roll

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Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with spina bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of spina bifida is growing rapidly and all data are subject to change without notice. Neither the SBA of Greater New England nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The SBAGNE does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. The SBAGNE does not employ medical personnel in its organization.

Operations

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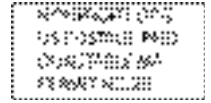


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Toll Free Phone: (888) 479-1900

Web site: www.SBAGreaterNE.org



CHANGE SERVICE REQUESTED

WE WANT TO STAY IN TOUCH



UPDATE YOUR MEMBERSHIP

FILL OUT OUR MEMBERSHIP FORM AT:

<https://sbagreaterne.org/resources/subscribe/>

TO MAKE SURE YOU RECEIVE UP-TO-DATE INFORMATION FROM
SBAGNE

DON'T MISS OUT ON ALL THAT IS HAPPENING WITH SBAGNE