

Winter 2020



SBAGNE

news

SBAGNE Remembers 2019

Year in Review



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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.

Join us for upcoming 2020 events

Put us on your calendar!

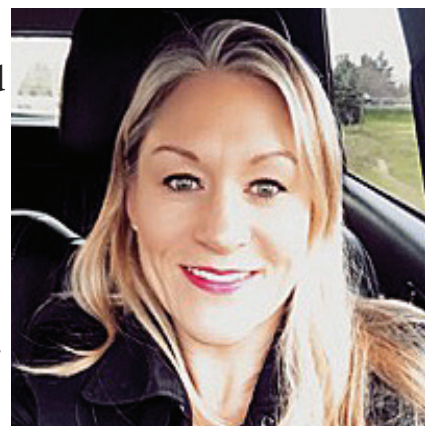
Join us for a 2020 filled with fun, connections, support, and resources. Check our website and social media for even more activities throughout the year!



Introducing our new board chair

Hello SBAGNE Members,

My name is Amy Bois and my husband is Steve. We are the proud parents to Tyler age 14, who was born with spina bifida and Andrew age 10. We reside in Greenland, NH. I am very excited to kick off the year as your new Board Chair! My goal is to bring our community together, offering exemplary programming, providing education and opportunities for those living with spina bifida and their families. We have a bright year ahead with BEST Meets BLIN'G in March, Adult Programming, Walk-N-Roll, UNH Browne's Center, 2020 Conference, and much more. I ask that you get involved even more this year and share it with anyone who will listen. We have such an opportunity to raise awareness, educate others, and show our communities what LIVING with spina bifida really looks like. I look forward to meeting many more of you and building an even more robust SBAGNE community. Alone we are STRONG, together we are even STRONGER!



Cheers to a wonderful 2020!

2020 Calendar

- January 25: Adult Group at Boston College Basketball Game
- February 8: Board of Directors retreat and planning day
- February 15: Adult Group at Boston College Hockey Game
- March 3: Adult Group at Gulu-Gulu Cafe Drink-N-Draw
- March 6-8: BEST Meets BLIN’G teen and tween weekend
- June 6: Adult Group Adaptive Sailing
- June 20: MA Walk-N-Roll and Summer Picnic
- July 11: BEST Meets BLIN’G teens, tweens, and siblings day
- August TBD: ME Walk-N-Roll and Summer Picnic
- August 16: New Balance Falmouth Road Race
- September 19: Tour de South Shore
- October 24: New England Spina Bifida Conference
- December 5: ME Holiday Party
- December 6: MA Holiday Party

Memorial Donations and Honorariums

We would like to recognize the following people for donating to SBAGNE in memory or honor of a loved one in 2019. We appreciate your thoughtfulness and generosity and extend our warmest wishes to you and your family.

In Memory of Maria DiSpena

Carol Tourgee
Eric Monzon
Lois Hixon
Philip Lynch
Joyce Guleserian
Lucille Cesari
Mr. & Mrs. Thomas Martello
Zenda Mancini
Joan & William Zapach
Colleen & Robert Hall
Mr. & Mrs. Stephen Danca
Maura Farrell-Kilbashian
Carol Passacantilli & Nicole DiSpena
Leo & Carrie Lermond & Family
Giacomo & Rhonda Dirado
Mr. & Mrs. Bob Kaplan
Paul S. Passacantilli Sr.

In Memory of Jeanne Ferraro

Jean Ellen Keras
Mr. & Mrs. Bob Allan
Robert P. Turnan
Janet Komarnicki
Jeanne Marie Oski
Mr. & Mrs. Bruce Brauninger
Mr. & Mrs. Hans Warnick Jr.

In Memory of Donald F. Fucci

Dorothy Garling
James Moreland
Joanne Larrabee
Lauren Mednick

In Honor of Jeremy Evans

Kirk and Sheila Joslin

In Honor of Chris Thomas

Kirk and Sheila Joslin

In Memory of Emily O'Malley

Michael Devere

In Honor of Josephine Elliott

Wells Fargo Advisors

In Memory of James E. Grip Jr.

Terence W. Lynn
Deborah Donovan Glover
Mr. & Mrs. Norman Fine
Mr. & Mrs. Daniel Russell IV
Mr. & Mrs. Kevin Kelley
Mr. & Mrs. Paul McGowan III
Audrey H. Dancewicz
Frederick R. Eichorn
Mr. & Mrs. Richard Shea
Penny O'Brien
Susan Gile
Mr. & Mrs. Linton Young
Cooney & Associates
Daniel & Deborah Lydon

In Memory of Francis Bernard Jr.

Ann Desrosiers
Ellen Poulos
Mr. & Mrs. Charles Jurgelewicz

In Memory of Jane Erikson

Joan Pratt
Mark Sims
Doug Henderson
Bill & Joann Richards
Patricia Darcy
Jeffrey Currie & Family

In Memory of Sarah Shorey

Katherine Jorgensen

In Honor of Mario Arteaga

Kirk & Sheila Joslin

In Honor of Luke Gagnon

Roland and Christina Gagnon

In Honor of Michele Whitney

Kirk and Sheila Joslin

In Memory of Cassandra DuMoulin

Connie Hemphill
Mr. & Mrs. Eugene Ryan

In Memory of Alan West

Mr. and Mrs. Joseph Tibbetts
Isabel Nickerson

In Memory of Maria Conley

Susanne Conley

In Memory of Baby Capansky

Eileen Morrison

In Memory of Donald Nutton

Bebe Karelitz
Diane Geragosian
Stephen Bennet

In Memory of Rosa Parker

Kenneth Wilkins Jr.

In Memory of Helen Mitchell

David & Myung Soon Woo
Roderick

In Honor of Sarah Archer
Kirk and Sheila Joslin

In Honor of Matthew Cadette
Kirk and Sheila Joslin

In Honor of Nivia Deleon and Jarelin Escobar

Kirk and Sheila Joslin

In Honor of Liv Walsh

Cathy and Warren Cooke

In Honor of Alex Danay

Kirk and Sheila Joslin
Dale Danahy

In Memory of Liam Milnes

Mr. & Mrs. Joseph Sciuto

In Memory of Patricia Forlizzi

Carol Passacantilli

From the Desk of Ginny Briggs

Dear Members,

It is hard to believe that the fall season is already behind us, and we have wrapped up another exciting and successful year here at SBAGNE. As I completed my two-year term as Board Chair this past December, I reflected on some of the major accomplishments and highlights of this incredible organization over the last year.

I will start by saying how very proud I am of our Board of Directors for their commitment, time, patience, and energy. It was my pleasure to serve on the board with each one of them, and I am grateful for their hard work and their friendship. I would also like to take a moment to thank Kirk Joslin, our Interim Executive Director, who helped us through a transition with our office staff. Kirk not only handed our day-to-day tasks in early 2019, but provided us with a very important assessment of our organization which will help us develop a new strategic plan this year. Kirk was also very grateful for our Operations Manager, Laura Lambert. Laura is our rock. She has stepped up on numerous occasions for SBAGNE, always willing and always doing a stellar job. Lastly, I am so pleased that Jean Bertschmann, our new Executive Director, joined us last July. She has done an absolutely amazing job. I am truly amazed at the amount she has accomplished in the few months she has been with us. We are fortunate to have her!



In 2019, we made changes to some of our regular events that worked very well. First, we combined our annual Walk-N-Roll with our summer picnic in both Massachusetts and Maine. This change increased attendance in both locations, and provided greater opportunities for families and individuals to meet, mingle, and engage in activities together. Second, we combined the BLIN'G (Better Living 'N Girls) and BEST (Boys, Esteem, Success, and Training) events for teen and tween girls and boys respectively. The feedback for this combined event was overwhelmingly positive and we are now in the process of planning the second combined event for March 2020.

Our regular fundraisers including the two Walk-N-Rolls, the Falmouth Road Race, the Tour de South Shore and the Annual Appeal did very well, raising a total of \$138,000 in 2019. I would also like to take a moment to thank our countless volunteers who made all our events and fundraisers possible. We appreciate their time and effort to help make all our gatherings fun and engaging ways to connect with our SB community. We encourage anyone interested in volunteering to contact our office. We would love to have you!

I am happy to report that I will serve one more year on the Board of Directors, so I may help with the transition to our new Board Chair, Amy Bois, and Vice Chair, Jason Paynich. I look forward to continuing my service to SBAGNE, in support of this wonderful organization and its constituents, which include my lovely daughter, Grace, who just started college! Without SBAGNE, life could have been very different for Grace and our family and for that we will always be grateful.

As I reflect on the exciting and productive year that is now over, I am grateful for the people who made it possible, and excited to think about what 2020 will bring. I wish you all a happy and healthy year and hope to see you soon.

- Ginny Briggs
Board Chair 2017-2019



Year In Photos

We celebrated the holidays last December in Maine and Massachusetts! Thank you to our committee members and volunteers for making these celebrations possible!



Year In Photos



SBAGNE hosted the first joint BEST Meets BLIN'G Weekend on March 1-3, 2019!
Thank you to everyone who made it such a successful weekend!





Year In Photos

The SBAGNE community celebrated the summer with our annual Walk-N-Rolls and summer picnics in Maine and Massachusetts.



Year in Photos



Our community raised \$138,000 for programs and events in 2019.
Thank you to all who donated, raced, walked, and rolled for spina bifida!



Our Appreciation

2019 Volunteers

We would like to thank everyone who helped organize this past 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 2020 programs or becoming part of a planning committee should contact Jean Bertschmann at jbertschmann@SBAGreaterNE.org.

Annual Appeal

Your generous support will help us expand and improve our outreach, programming, and financial support to families and individuals living with spina bifida across New England. 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://sbagreaterne.org/get-involved/make-a-donation/>.

2019 Sponsors & Grantors

Constance O. Putnam Foundation
Joy in Childhood Foundation
DCU for Kids
Matthew V. Joslin Fund
Blue Cross/Blue Shield, Eurest Dining Services
Boston Children's Orthopedic Surgery Foundation
Boston Pediatric Neurosurgical Foundation
Hollister
Wellspect
Ms. Wheelchair Massachusetts
Adaptive Sports New England
Spaulding Adaptive Sports
Pediatric Associates of Lewiston
Northeast Passage
Kennebec Pharmacy & Health Care
Arbella Insurance Foundation
Milford Federal Savings Bank

3rd Party Fundraisers

The Friendly Toast: \$2,886
Amy Bois: \$1,155
Alex's Ride: \$1,064
BayCoast Bank: \$920
T-Stop Superette: \$900
Lindsay Resto and Lularoe: \$500
Kristin Lovering Marquis: \$350
Maria Pereira: \$285
Joshua Adam Wade: \$260
Stop & Shop: \$113
Noelle Gilmore: \$100
Mark Grodzicki: \$90
Michelle Morotz: \$80
BigY: \$51

You can be a 3rd party fundraiser too! It can be as simple as starting a **Facebook fundraiser**. Other fundraisers have included: dress-down days, local restaurant programs, and birthday events. Contact llambert@sbagreaterne.org for more information on how to become a 3rd party fund-raiser.

Programs and Resources

SBAGNE Empowerment Program

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

This \$200 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.

Jean Driscoll “Dream Big” Award

SBAGNE offers this \$1000 award as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult living with spina bifida. SBAGNE is seeking to support an individual in “pursuing their passion” as Jean Driscoll has in her life. The award may be used for educational, developmental or assistive programs and needs and will be awarded to a SBAGNE constituent over the age of 14, with spina bifida who best demonstrates the character and determination of the scholarship’s namesake. An individual can self-nominate or be nominated by another. If you’re interested in applying, download the application form at www.SBAGreaterNE.org.

Supply Distribution

We are currently holding a donation of catheter supplies. If you are interested in receiving any, please contact our office at 888-479-1900 or llambert@sbagreaterne.org for more details or to arrange pick-up. This offer is available while supplies last.

Available products include:

Cure: Cure Twist

Hollister: Onli Ready to Use

Hollister: VaPro Plus Pocket

Hollister: Apogee HC

Coloplast: SpeediCath Standard

Covidien: Sure Care Bladder Control Pads

Guidelines for the Care of People with Spina Bifida

The national Spina Bifida Association has released 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. You can access this resource by going to:

<https://www.spinabifidaassociation.org/guidelines/guidelines-by-age/>

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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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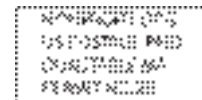


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CHANGE SERVICE REQUESTED

WE WANT TO STAY IN TOUCH



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<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