

Summer 2020

SB SBAGNE

news

SBAGNE 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

I hope everyone is enjoying their summer and finding time to relax and soak in this fabulous weather we have been having. We are continuing to move forward with fundraising during this time and doing our best to provide a quality virtual experience. While Walk-N-Roll did not achieve its fundraising goal of 30K, we are encouraged that many tuned in for the wonderful programming we put together for this event. Thank you to everyone who attended and especially to our sponsors. Without you, this would not have been possible.

The Falmouth Road Race Team has started to pick up steam with their fundraising efforts. We ask that you support our team members in any way you can by sharing their stories and raising awareness. Every time we share in our communities, we are showcasing how much SBAGNE impacts those living with spina bifida and how their donations make a big impact. Thank you to everyone who is participating this year!

In addition, we are looking for people to participate in our virtual Tour de South Shore team this year. This event has something for everyone, from the avid cyclist to a 5K Fun Run/Walk. Stay tuned for more details on how to get involved.

As we gear up for back-to-school, now more than ever it is important that we come together as a community. School will look different for many and we will continue to provide quality programming that will help our members stay informed, engaged, and, most of all, provide much needed social interaction.

Thank you, again, for your continued support. I am so proud to be your Board Chair & look forward to seeing you ALL again in-person!

-- Amy Bois



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
- July 15-18: All New England Virtual Walk-N-Roll/Summer Picnic
- July 26: Teens, Tweens, and Siblings Virtual Day at the Browne Center
- August 16 - 29: New Balance Falmouth Road Race "At-Home"
- September 19: Tour de South Shore
- October: Awareness Month
- October 25: World Spina Bifida Day and National Walk-N-Roll
- December 5: All New England Virtual Holiday Party

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:

- October Educational Webinars
- Virtual Paint Nights

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 Honor of Emily Lane

Catherine Nicastro

In Honor of Sarah Rafala

Barbar Bo Rockwell

In Honor of Patricia Forlizzi

Carol Passacantilli

In Memory of Jean Ferraro

Robert Bazinet

In Honor of Kristin Marquis

Madeleine's Daughter Bridal

In Memory of Nicole Bongiolatti

Lee and Cathy Bongiolatti

In Memory of Dennish 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 Memoy of Gary Lewis

Rich Robinson

Ronald & Patricia Stachowski

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 Connelly

John Edwards

Joseph Connelly

Monica Nakielski

Nancy Burns

Judith A. Castricone

Mr. & Mrs. Joseph Connelly

Diane 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

From the Desk of the Executive Director

Dear SBAGNE Family,

I hope this newsletter finds you healthy and well, and able to take advantage of the warm summer breezes and some outdoor activities.

In my first year at SBAGNE, what has really struck me is how supportive and resilient this community is. It has been a pleasure to have met so many of you, and I am grateful to you for sharing your stories, your hopes, and your needs with me. I am proud to be part of an organization that is so inclusive and welcoming. I look forward to meeting many more of you once we are able to gather again in-person -- what a celebration that will be!



2020 has certainly been a very challenging year for all of us. Please know that Laura and I are working hard to find new ways to support our community during the pandemic. We have a list of COVID-19-related resources available for you, as well as a big supply of catheters for anyone who has a need. We have been supporting some equipment exchanges, so please reach out if you have equipment to pass along, or if you have a need for new equipment. There is still funding available for Empowerment Grants, and we encourage members to apply for this financial support.

We have been offering a lot of virtual programming, and have had more than 200 participants so far - there is always room for more! We had a wonderful virtual Walk-N-Roll and Summer Picnic, rich with resources from every state and some well-wishes from Jean Driscoll, Daniel Romanchuk, and Enock Glidden. Please check out the event page on Facebook, or send us an email for information.

Although we had to postpone our Conference, we are working hard to create some excellent virtual content to share during October Spina Bifida Awareness Month, including a collaboration with the national SBA and all other chapters on World Spina Bifida Day. We are going to make some noise on October 25th!

Finally, we are looking ahead to better days and making plans for in-person programming in 2021. We hope some - or all - of these programs will provide value to you, and we are very open to suggestions for new activities.

In closing, I hope that you will stay healthy, stay engaged, stay strong, and stay in touch. We miss you!

-- Jean Bertschmann



From the Falmouth Road Race Team Captain

Dear Members,

My name is Dave Balardini and this is my 14th year running the Falmouth Road Race for SBAGNE. Each year, I run in memory of my college roommate, Mike DesLauriers. We went to Westfield State University together (Go Owls!) where he was a music major. I run each year to keep his memory alive and as a promise to his family. It is truly an honor to run and raise funds for such a wonderful organization. I am thankful for my family, friends, and alumni, from all over who give generously to this cause.

When I was a freshman in college, I had never heard of spina bifida. I knew that my roommate was cool, his family was awesome, and we had fun together. The little things like staying up every night watching David Letterman or ordering Dominoes or the occasional kegger (off-campus of course!) made up for the fact that Mike walked slowly with crutches, wore leg braces, and had a wheelchair “just in case.” The other guys on our floor were envious of me because we were in a double room, not a triple, and Mike was kind, nice, and funny...and so patient to have lived with me for two years!



Although Mike had spina bifida, he didn't let his disability get in the way of doing anything he wanted. He navigated a campus which, at the time, was not very accessible (now it is very accessible). He made it to all his classes, studied hard, and still had fun. Amazingly, he never complained and never, ever said he couldn't do something. When I am reminded of his challenges, mine seem so minimal. This is what keeps me running year after year.

There's always a group of SBAGNE members cheering the runners on during the race. When they see me in a “Racing for Spina Bifida” singlet, they cheer loudly. I think of those families, like Mike's, who are strong, have fun, and never give up. This is what gets me over the big hill at the end and to the finish line.

This year's virtual Falmouth Road Race brings me the same joy, knowing that I am running for a great cause with the support of the staff and my team of runners. Please keep us in your thoughts as we run, fundraise, and challenge ourselves knowing that you, as members, motivate, and inspire us.

Thank you,

Dave Balardini

BEST Meets BLING



SBAGNE hosted a joint BEST Meets BLIN'G Weekend on March 4-6, 2020! Thank you to everyone who made it such a successful weekend!





Our Virtual Activities

The SBAGNE community is still coming together in virtual ways to support one another and grow together!



Since the COVID-19 pandemic began, we have been offering our services, programs, and activities through virtual means. Visit our Facebook page to watch story times with staff from the Boston Children's Spina Bifida Clinic, or watch messages from other SBAGNE participants! You can also visit our Facebook page to watch Tyler and Amy Bois interview pro-athletes with spina bifida!



Our Virtual Activities



Join us for virtual activities throughout the rest of 2020. Reach out to us at llambert@sbageaterne.org to learn more.



Join us for one of our virtual Adult Group Happy Hours or Quaranteen Zoom Hang-outs! And don't forget to stop by our All New England Walk-N-Roll and Summer Picnic event page on Facebook to check out all the adaptive activities and exercises, local resources, and special messages from our celebrity guests like Daniel Romanchuk, Enock Glidden, and Jean Driscoll!

Jean Driscoll “Dream Big” Award Nominee: Thalia Almeida

Before I begin to share with you my mission in fulfilling my academic pursuits, allow me to introduce myself first. Hello, my name is Thalia Almeida. I live in Waterbury, Connecticut and I am 15 years old. I am currently a high school sophomore and I attend Kaynor Technical High School. Kaynor Tech is a high school that not only focuses on academics but focuses on career trades as well. With that being said, I am in the Electronics Technology trade where we focus on building and analyzing circuits that are composed of many different electrical components that are soldered onto a motherboard. I am a teenager living with spina bifida. However, I do not let it stop me whatsoever. I believe that having spina bifida only makes me stronger and more determined to do things that people may say I am not able to do. It does not deter me from accomplishing my goals in life and it never will. Due to my determination, it has led me to do incredible things. I have been involved in many activities that most able-bodied people might question a disabled person doing, those which include cheerleading, baseball, swimming, tennis, volleyball, ballet, ice skating, water skiing, and even winning first place in the wheelchair division of an adaptive mud run. The determination that I show as a person living with spina bifida is just as outstanding in my academic performance.

As I had stated before, I am a high school sophomore at Kaynor Technical High School. Meanwhile, I am also taking online courses at Post University in Waterbury, Connecticut. I am taking them through a program that they offer called High School Academy. I am taking these classes because I believe that this is a perfect opportunity for me to attain some college credits while on the journey to earning my high school diploma. As a matter of fact, my plan is to potentially attain my associate’s degree along with my high school diploma and a certification in my trade. I plan on obtaining my degree in marketing, and then moving forward to getting by bachelor’s degree in psychology. Psychology is something that I have been aspiring to pursue for quite a while now. The reason for this is simply because I love and enjoy helping people. I like when people come and talk to me whenever they have some sort of issue that they need help with, not just psychologically, but in general. It is validating when you know that you are a person that can be counted on and that people find you very helpful to talk to. I enjoy the counseling aspect of psychology so much I, as a matter of fact, plan on opening a private practice one day where I can counsel people, preferably in the teenage to young adult range, and help them resolve any conflict, whether it be a mental health disorder or just a general conflict within themselves or their daily life. However, there is no associate’s program for psychology. However, that is okay because marketing is another career that sounds interesting because I believe that I am good at persuading someone to see my perspective of things.

Thank you for taking the time to learn more about me and my goals in life. I consider it an honor to be nominated for the Jean Driscoll “Dream Big” scholarship award. As I hope that I have shown you, I am a very determined person and I am willing to take on any challenge that comes my way. I truly believe that this scholarship will help me in my quest for continued education.

Yours truly,
Thalia Almeida



Jean Driscoll “Dream Big” Award Nominee: Abigail Bemis

I’ve always been a dreamer. From childhood, I was always interested in how the world could be different. I devoured fantasy novels and Disney movies. I loved how there was always some aspect of these fantasy worlds that seemed to be better than the real world. I was inspired to become a writer so I could make a better world. As I got older, I became more interested in science and math. I soon realized that by pursuing a career in engineering, I could combine my scientific interests with my desire to improve the world. My dream is to pursue a career in engineering in a company that is making huge strides in technological development or in a research position at a university. Either way, I want to keep learning and pursue an education up to a doctoral degree and beyond.

For me, one of the most important parts of my journey to becoming an engineer has been finding opportunities to explore my interest in STEM subjects, mainly through summer and after-school programs. I have explored areas from robotics (ZERO Robotics) to stem cell research (MIT HSSP). Each program I participated in gave me this opportunity, but one in particular helped me grow as a person. MIT LLRISE (Lincoln Laboratory Radar Introduction for Student Engineers) is a program for rising high school seniors run by MIT Lincoln Laboratory to introduce students to radar technologies and electrical engineering. The experiment-based nature of the program allowed me to challenge myself and gave me the hands-on engineering experience I had been looking for. Besides the academic aspect, LLRISE gave me a unique opportunity to push the limits of how my spina bifida affects my independence. LLRISE is a two-week-long residential program, which was new for me. Before LLRISE, I had experience living without my parents at Camp Spifida, but living in a place where I was the only one who understood my medical issues was a terrifying prospect. For the first time, I would have to manage medications and bowel and bladder management on my own. As it turns out, this limited external support that I was so worried about was the push I needed to be confident in my own abilities. I learned that I am capable of being independent and successful. I can thrive with my disability.

Right now, my freshman year of college creeps ever closer. Like most people, I’m nervous, but I’m excited for the opportunities I have in store. I’m thankful that I had the opportunities to participate in all of the STEM programs I did. I’m confident that my choice to study engineering was the right one, and I’m glad I was able to gain confidence. Even though my spina bifida can make day-to-day living challenging. I won’t let it stop me from pursuing my education. I’m so excited to say that I will be studying engineering at Northeastern University in the fall, and that my dedication won me the Women in Engineering Connections Scholarship. I know that there may be bumps along the way, both because of my disability and otherwise, but I’m looking forward to the future.

-- Abigail Bemis



Jean Driscoll “Dream Big” Award Nominee: Anthony DiSpena

I always considered myself to be a dreamer. Throughout my life, I saw myself in the shoes of the protagonists in classic Disney films. Characters who at first seemed like all odds were against them; whether they were made of wood, had flippers instead of feet, or turned into a frog by an evil voodoo spellcaster. Despite these obstacles, these cartoon characters achieved their goals at the end of the movie by conquering their fears and staying determined on their dreams.

This theme has played a large role in my life. Although I am not a puppet, mermaid, or frog, there have been many times in my life where my dreams seemed unreachable due to spina bifida. But that does not stop me, I still wish upon a star and dream big.

I have always gotten an adrenaline rush while debating others, and always make sure to prove my point. I love playing devil’s advocate with every opinion that I hear. I am also interested in how the legal system works and what powers and rights certain groups have. I sometimes look up laws or court rulings in my free time. If I could, I would, one day, become a justice on the Supreme Court of the United States! Through my tenure, I would be an advocate for disabled people who have gone through similar struggles as I.

To achieve this dream, I will be studying Political Science at Providence College in Rhode Island this fall. I was always concerned about leaving home and living on campus due to the countless medical procedures I have to go through due to spina bifida. However, I have taken precautionary steps to prepare myself for living away from home. With my preparedness and perseverance, I know that my dreams will come true.

--Anthony DiSpena



About the Jean Driscoll “Dream Big” Award

This year, through an unusual, anonymous donation, SBAGNE was able to give this award to four worthy nominees. Congratulations to Katie Packard, Abigail Bemis, Thalia Almeida, and Anthony DiSpena. SBAGNE offers this award as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult living with spina bifida. By offering this award, SBAGNE supports individuals in “pursuing their passion” as Jean Driscoll has in her life. An individual can self-nominate or be nominated by another.

We were very lucky to be able to have the awards announced by Jean Driscoll herself this year. Visit our [Facebook page](#) to watch the virtual award ceremony and read the essays of the award winners in pages 7-10!

Jean Driscoll “Dream Big” Award Nominee: Katie Packard

My big dream is to become a preschool teacher, especially one who works in an integrated setting, with kids of all abilities. When I was in high school, I thought I wanted to be a child life specialist. However, after volunteering several summers at our local integrated preschool, I realized I wanted to be a preschool teacher. But before I become a preschool teacher, my plan is to be a paraprofessional for a couple years. I want to be a paraprofessional first because I still want to have more time to learn the ropes of how a preschool classroom runs. Secondly, I am also still in the process of passing certain teacher licensing exams. I ultimately want to end up as a preschool teacher because I want to be a part of my future students’ educational and social growth. I also want to show them that you can obtain any job or dream that you have if you work hard and don’t give up. I believe that even if a person has a disability, she shouldn’t let what others might think hold her back. I have been working towards my goal by attending and graduating from Merrimack College. During my time at Merrimack, I studied Early Childhood Education and Human Development/Human Services.

Throughout my time at Merrimack College, I had many opportunities to practice working with young students of all abilities. I completed three semesters of student teaching at three different schools. While I was showing what I was capable of doing in the classroom, I was also able to observe my host teacher and see what she did in her class that I could also do in the future. Throughout my time at the schools, I was able to assist the teachers in preparing their daily lessons and activities. This allowed me to learn what content is most important to teach at certain points of the year. While I was working at the schools, I was also able to make connections with the staff and express my interest in working at the schools in the future.

Right now, I am in the process of applying to these schools among others for a paraprofessional position. However, with so much that is unknown about how schools are going to look in the Fall because of COVID-19, I am unsure what the status of my employment will be. With that being said, I am certainly not going to stop trying to find a job at a school in some capacity next year. I am also going to continue working towards passing my teacher licensing exams in the hopes of reaching my dream goal of becoming a preschool lead teacher in the near future.

-- Katie Packard



Our Appreciation

2020 Volunteers

We would like to thank everyone who helped organize this year's activities so far. 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.

Mid-Year Appeal

We held a mid-year appeal in April to help off-set some of our funding loss brought on by the coronavirus pandemic. We thank everyone who gave to help support our continued services through virtual means during this unique and difficult time.

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/>.

2020 Sponsors & Grantors

Constance O. Putnam Foundation
Boston Children's Pediatric
Neurosurgical Foundation
Boston Children's Urological Foundation
180 Medical
Hollister
Coloplast

Recent 3rd Party Fundraisers

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)
Stop & Shop (Bags 4 My Cause)
Colette Bither (Facebook Fundraiser)
Xaimara Angel Xiolana Xax (Facebook Fundraiser)
Katie O'Leary (Facebook Fundraiser)
Chrome Angelz: Misfitz & Heathenz Chapter
Sarah Rafala (Facebook Fundraiser)

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, 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.

National Education Days

The national Spina Bifida Association is hosting several education days on “Living Well with Spina Bifida” in August and October.

August 8, 2020

October 3, 2020

October 17, 2020

October 24, 2020

If you would like to participate in one of these events, please use the link below to register or learn more.

<https://www.spinabifidaassociation.org/education/education-days/>

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.”

Supply Distribution

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 through our website.

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

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](#)

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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.

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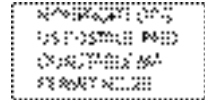


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Web site: www.SBAGreaterNE.org



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