Summer 2019

SBAGNE
news

SBAGNE Celebrates the Summer

Walking and Rolling for Spina Bifida

SBAGNE
news

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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 it goals with a personal or matching donation. Visit **SBAGreaterNE.org** today to contribute.

Upcoming Events

ME Walk-N-Roll/ Summer Picnic

Join us for a fantastic day of awareness, community, and summer fun!

Saturday, August 10, 2019
Pineland Farms
New Gloucester, ME

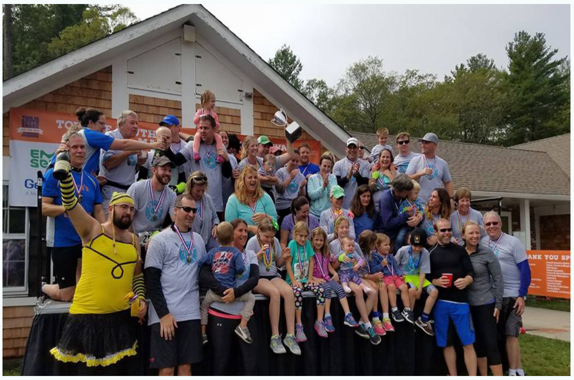
9:45AM-10:15AM -- Registration
10:30AM-11:00AM -- Walk
11:00AM-1:00PM -- Community Picnic/Resource Fair and Photos with Princesses
12:00PM-1:00PM -- Northeast Passage Adaptive Sports
1:00PM-3:00PM -- Visit to Pineland Farms
2:00PM-2:30PM -- Brushing a Bunny Farm Activity

Visit **https://sbagreaterne.org/** to start fundraising or to register for the picnic! Thanks to our Maine Regional Committee for all their hard work and dedication!

Falmouth Road Race

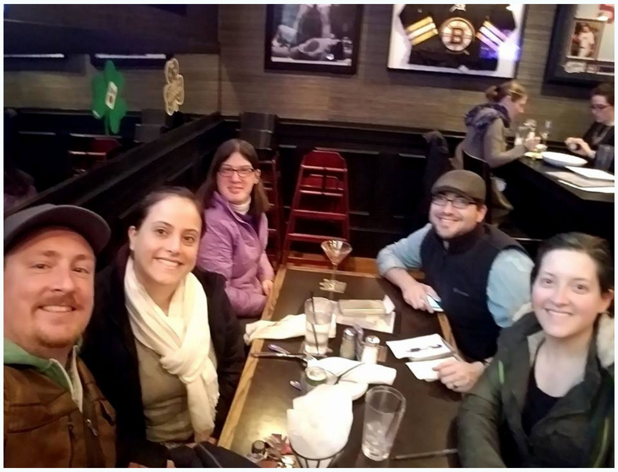
Our Falmouth Road Race team is busy training to run the race on August 18th! If you want to support the team, go to their fundraising page at **https://www.crowdrise.com/o/en/campaign/spina-bifida-association-of-greater-new-england**. Email **llambert@sbagreaterne.org** with any questions.

Tour de South Shore



From a 5K walk to a 50-mile bike ride, this fundraiser organized by the McCourt Foundation has it all! Participate on Sept 21st to enjoy autumn on the South Shore while supporting SBAGNE programs and help the team return to defend their title as fundraising champions! This year, the race will include a wheelchair start for the 5K race! Thank you to the Holleran family for getting us involved. Email Dan Holleran at **dholleran@sbagreaterne.org** to join the team. You can also donate to or join the team at **https://give.mccourtfoundation.org/team/237725**.

Adult Group



Our group for adults living with spina bifida (18+) meets monthly for dinner and is a fun means of peer support. Attendees are welcome to bring a friend or family member. RSVP to **llambert@sbagreaterne.org**. SBAGNE schedules and books adult group dinners. At this time, we ask attendees to cover their own meal expenses.

Upcoming dinners:

Aug 30th, 6:30PM -- Lucy's Tavern, Dorchester, MA
Sept 27th, 6:30PM -- Wahlburgers, Hingham, MA
Oct 25th, 6:30PM -- Double Chin HK Cafe, Boston, MA

2019 Abilities Expo

SBAGNE will be returning to the Boston Ahilities Expo from September 13-15. This event helps you connect with organizations like ours, test cool, new assistive devices, and try out adaptive sports and recreation. We hope you'll stop by our table to say hello! Or you could spend a few hours representing SBAGNE! Email **llambert@sbagreaterne.org** if you would like to help cover our booth, meet prospective members, and talk about your favorite SBAGNE programs! Learn more about the Abilities Expo at **https://www.abilities.com/boston/**. This event is free and open to the public.

Memorial Donations

We would like to recognize the following people for donating to SBAGNE in memory of a loved one who has passed since the beginning of 2019. We appreciate your thoughtfulness during a time of grief and extend our condolences to you and your loved ones.

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 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

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 and Joann Richards
Patricia Darcy
Jeffrey Currie & Family

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

From the Desk of Jean Bertschmann

Dear Members,

Happy summer! I am honored to be selected as the new Executive Director for SBAGNE, and very much looking forward to meeting you all at our upcoming events! My background is in public education and small to medium non-profits, and the opportunity to work at SBAGNE with members across New England and as part of a national organization is very exciting for me. On a personal note, my husband and I have four daughters and we live in Hopkinton, MA, very close to the SBAGNE office. In my leisure time, I love to spend time at the Cape, read, and quilt.

We had a wonderful turnout at the Massachusetts Walk-N-Roll & Summer Picnic. Over 150 people enjoyed a beautiful day of walking, rolling, swimming, sledding, and hoops, capped off by a pontoon ride on a beautiful lake. The Maine Walk-N-Roll & Summer Picnic looks equally exciting - we will be at Pineland Farms in New Gloucester, ME on Saturday, August 10th for a fun day of walking, rolling, petting bunnies, exploring adaptive sports options, and touring the farm. Please join us!

Summer fun continues with our Falmouth Road Race team running on Sunday, August 18th, the Abilities Expo September 13-15, and the Tour de South Shore on September 21st. Please see the highlights and links in the newsletter for information regarding how you can participate. In particular, we are looking for Tour de South Shore participants and volunteers to join us at the Abilities Expo. I invite you to help us staff the table over the three days so that we can connect with our members, invite new members to join, and reach out to partner organizations to expand the programming that we now offer. If you are interested in volunteering, please email me at **JBertschmann@SBAGreaterNE.org**.

Laura and I are busy planning Holiday Parties and our events for next year. We would love to hear from YOU! Please drop us an email or give us a call and let us know how we can better serve you.

In SBA National news, please check out their updated website for many new resources. In particular, the Guidelines of Care for People with Spina Bifida: **https://www.spinabifidaassociation.org/guidelines/guidelines-by-age/**. This is an excellent resource to share with your medical providers, school nurses, etc.

My sincere thanks to the Board, and the members whom I've had the pleasure to meet already for the warm welcome to SBAGNE. I'm very grateful to Kirk Joslin for his incredible work during the transition and for his insight and advice. Laura Lambert has done a phenomenal job of keeping programs up and running and we are looking forward to being able to expand what we can offer you in the coming year.

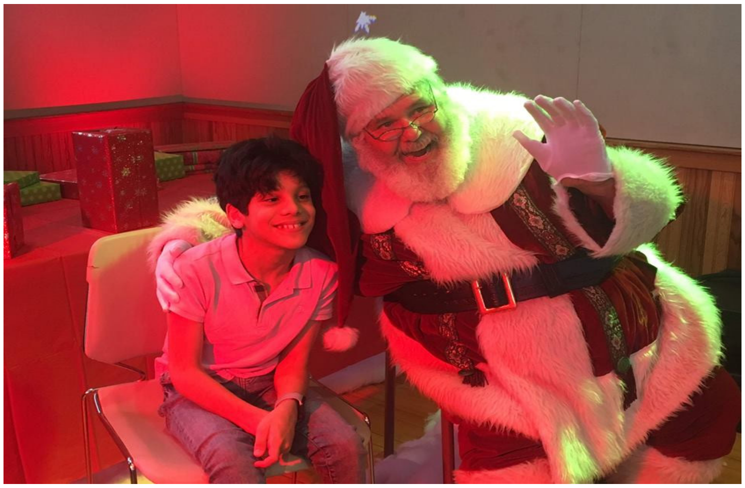
I look forward to working with all of you in the coming months and years. Cheers to the end of summer and the beginning of our adventures together!

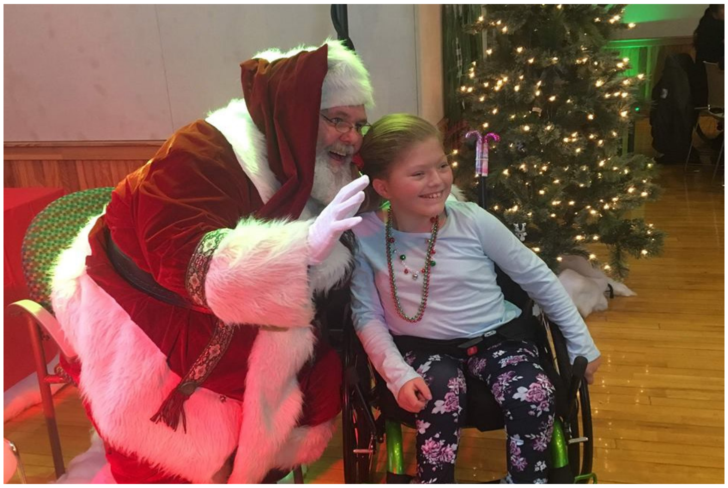
Best —

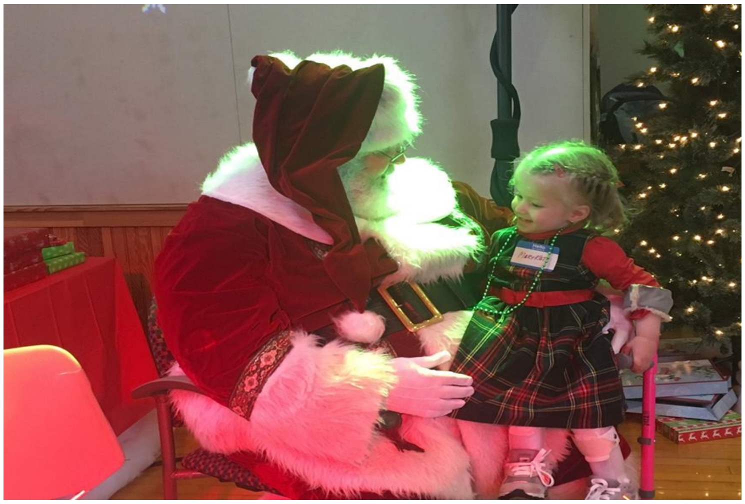
Jean Bertschmann
Executive Director

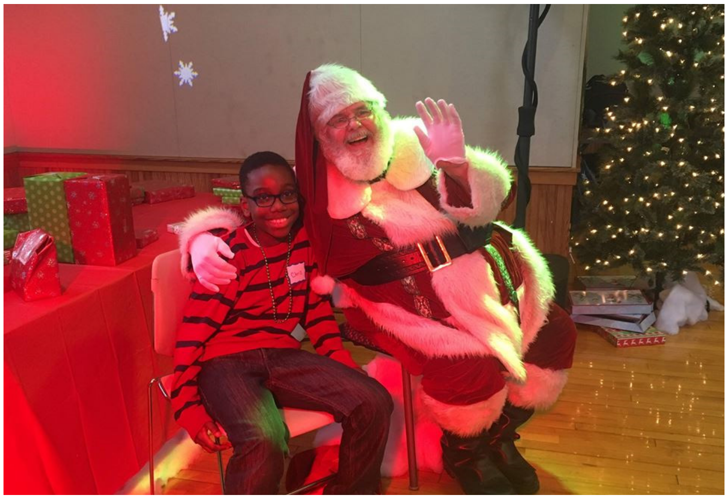
Celebrating the Holidays

We celebrated the holidays last December at the Weston Community Center in Weston, MA! We were visted by Santa, exchanged gifts, played games, danced to tunes by our DJ, Cody Bertrand, made crafts and ate holiday treats to our hearts' content! Thank you to our Holiday Party Committee Chair, Jason Paynich, our holiday gift shopper, Rebecca Sherlock, Our volunteers from Quincy College, and everyone else who made the event such a success!





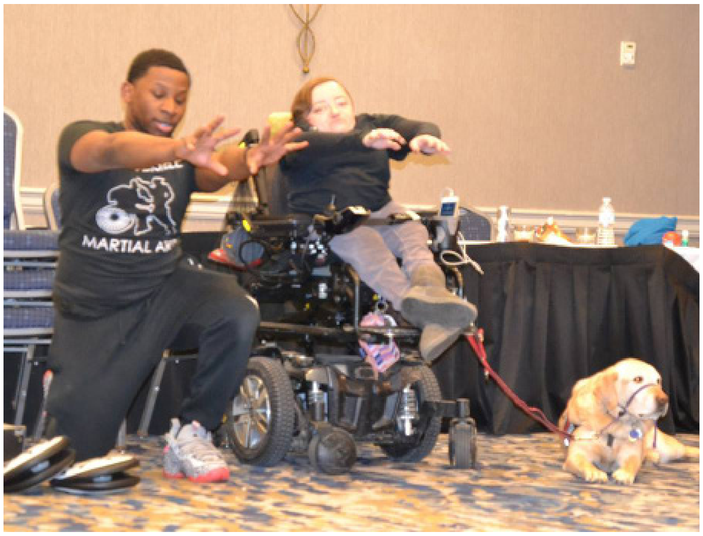


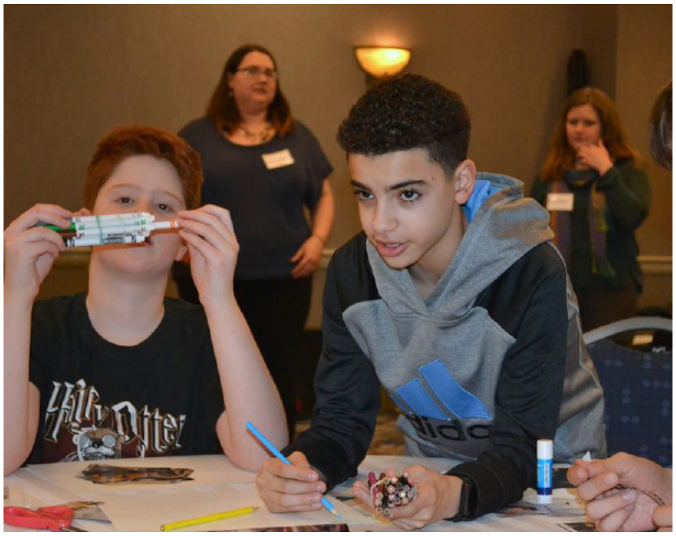


In the News

BEST Meets BLING Weekend

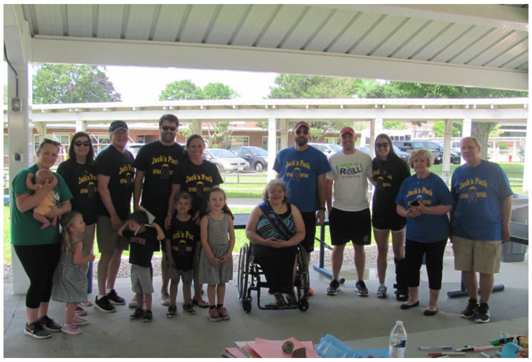
SBAGNE held its first joint BEST Meets BLING Weekend on March 1-3, 2019! The first co-ed weekend for teens and tweens living with spina bifida was filled with fun and excitement. The weekend included activities and presentations on adaptive sporst and recreation, attending college with a disability, improve acting and much more! Thank you to all our volunteers, presenters, leaders, mentors and participants!

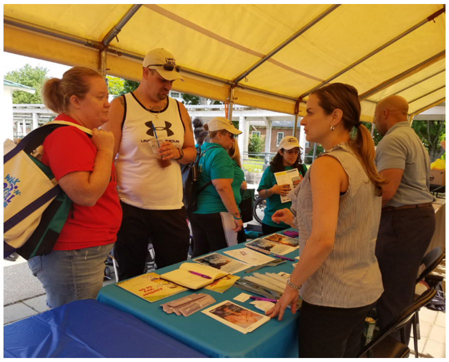


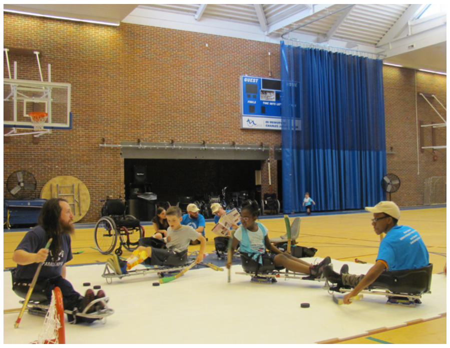


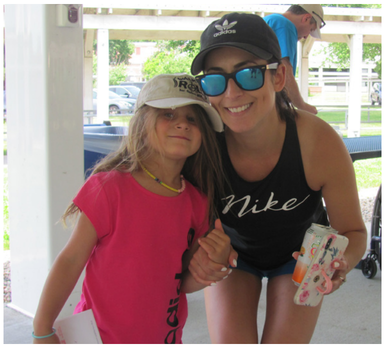
Bringing in the Summer

The SBAGNE community brought in the summer on June 22nd with the Massachusetts Walk-N-Roll & Summer Picnic! We raised awareness and funds for programs and support, enjoyed a picnic lunch sponsored by Eurest Catering, met vendors at our resource fair, were awed by magic tricks by Great Scott, swam in the pool, tried out sled hockey, and went for boat rides on the pond. The day was filled with fun and friendship! Congratulations to our top 3 teams: Gagnon Gang who raised $5,725, Tyler's Troops, who raised $4,065, and Jack's Pack who rased $2,275.

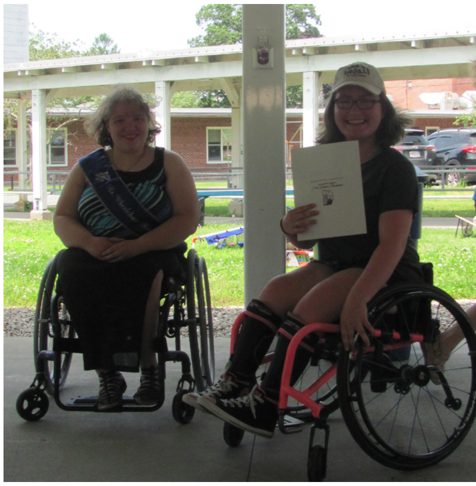








Introducing the 2019 Jean Driscoll Award Recipient



Elaina Cardenas is a 16-year-old with a passion for ballroom dancing. Elaina uses ballroom dancing as a way to balance her life, alleviate her worries and stress, and surround herself with empowering and supportive people. She looks forward to using her Jean Driscoll Award to increase the dance classes she can take as she pursues her goal of becoming a professional ballroom dance teacher. She has been dancing for 7 years and has no plans to stop!

Acceptance and Community

In March of 2016, I attended my very first BLING Weekend (ever) as a volunteer mentor. At this time, I was experiencing the drive to do something that had not been a part of my life before: to get more involved with the spina bifida community. I wanted to meet more people like me, to share experiences with peers and girls younger than me, to connect, to look spina bifida dead on and embrace it. There was no doubt in my mind that BLING and BEST were exactly what I was looking for. It felt like the perfect way to jump in and embrace the community that, for so long, I wasn't sure that I felt a part of.

Fast-forward to today. I've returned to BLING Weekend for four consecutive years, and this year I played a much larger part in the event as "lead" mentor, thanks to the support of SBAGNE Chairperson, Ginny Briggs, and my fellow mentors. This year was also different because the girls' BLING Weekend was combined with the boys' BEST program. This was an absolute blast! Seeing all of the kids (and parents too!) bonding, talking, having fun, and sharing experiences is one of my favorite parts of the whole weekend. This is what this program is all about, in my opinion: providing young people and their parents or families with the opportunity to spend quality time with peers. At the same time, it allows us as mentors to do the same thing. We share our stories with the kids and parents and often find that we have a lot in common. Some great friendships that I treasure have come out of this experience. These friendships are unlike any others I've had before because they are with other individuals living with SB. This is another experience I didn't know I had been missing out on and I'm so thankful to this program for bringing it to light.

The role that this program plays in all our lives boils down to two words: acceptance and community. When asked what the best part of the weekend was, one of this year's attendees responded, "Everything! But I'm just excited to be around other people with disabilities." To simply be around people who move like you, look like you, experience the world like you do, is something that we as people with SB don't always get to experience in our daily lives. But, with the community that SBAGNE continues to form through programs like BLING/BEST, we are creating more and more opportunities for this to happen and that is a beautiful thing.

> ***To be around people who experience the world the way you do is something we don't get to experience in our daily lives.***

I leave BLING Weekend each year feeling quite emotional. I've learned along this journey that finding your community, sharing your story, talking about your victories and hurdles, makes a gigantic difference in not only your own life, but in the lives of others. We are all in this together.

Amie Richards
BLING/BEST Volunteer Mentor
SBAGNE Board Member

Walk-N-Roll/ Summer Picnic Thank you

We would like to thank everyone who helped organize this year's summer activities. Your involvement in our Summer Picnics and Walk-N-Rolls helped make it possible to bring the community together, celebrate the summer, and raise awareness and funds for programs and support for the Spina Bifida Community!

Thanks to our MA Walk-N-Roll/Summer Picnic Committee and volunteers:
John Wendell
Amie and Max Richards
Kristin Marquis
Jason Paynich
Jan Terlaje

Thanks to our vendors and sponsors:
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

Thanks to our ME Walk-N-Roll/Summer Picnic Committee:
Jamie Curtis
Sarah Haywood
Emily Cooke

Thanks to our vendors and sponsors:
Pediatric Associates of Lewiston
Northeast Passage
Hollister
Kennebec Pharmacy & Health Care

BEST Meets BLING Thank you

We would like to thank everyone who participated in this year's BEST Meets BLING Weekend. We look forward to seeing you again next year! In the mean time, our mentors are coming up with new ways to keep the BEST/BLING community in touch year-round.

We thank our Board Chair, Ginny Briggs for assembling a fun and interactive schedule filled with activities.

Thanks to this year's mentors and volunteers:
Amie Richards
Jeremy Evans
Lena Williamson
Ethan Linsky
Sheila Joslin
Linda Long-Bellil

Thank you to our presenters:
Keja MacEwan - Spaulding Adaptive Sports Center
Paula Coccee - Curry College
Patrick Remy & Team - Easter Seals
Dan Harris - Center for Independent Living
Kristin Marquis - Madeline's Daughter
Joe Walsh - Adaptive Sports new England
Improv Actors - ImprovBoston

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 Epowerment benefits are awarded monthly.

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

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:
Hollister: Onli Ready to Use
Hollister: VaPro Plus Pocket
Hollister: Apogee HC
Coloplast: SpeediCath Standard
Covidien: Sure Care Bladder Control Pads

REquipment

REquipment is a non-profit that collects and distributes refurbished durable medical equipent for free! They even have a delivery service available for a small fee.

If you are in the market for a new piece of durable medical equipment or are looking to give away DME you currently own, visit **https://dmereuse.org**. You can start searching for new equipment using their inventory available online or check their list to learn about what kinds of equipment they accept as donations.

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.

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