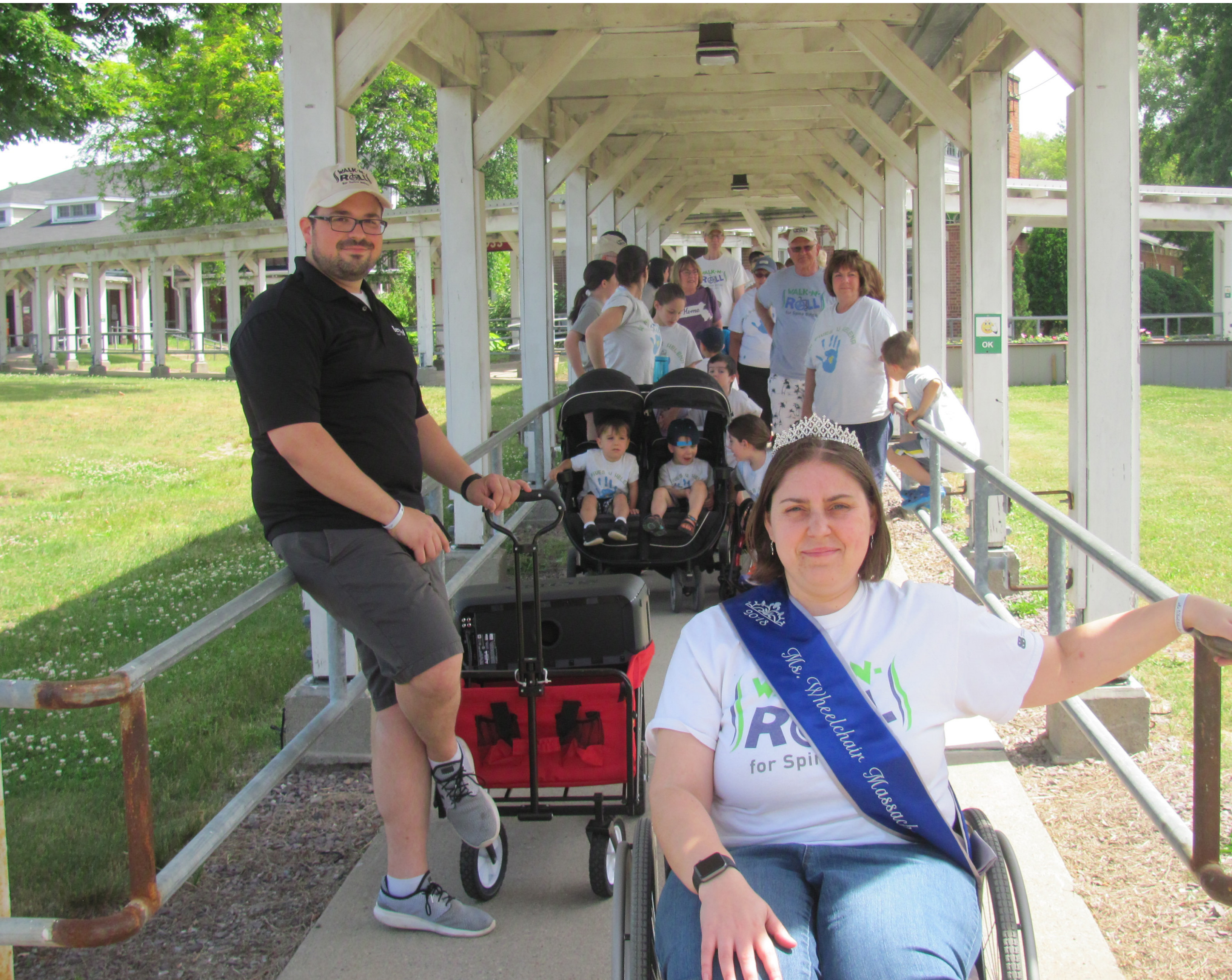
Summer 2018

SBAGNE news

SBAGNE's Annual Walk-N-Roll

starts summer in Massachusetts off right



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

Upcoming Events

Maine Walk-N-Roll

Join us for the Maine Walk-N-Roll on September 22, 2018 at 9 AM for registration and 10 AM for the walk. Meet us at Capitol Park, 33 Union Street in Augusta, ME. Help us reach our goal of $10,000, compete for door prizes and for a grand prize resort stay in Antigua. Raise $100 to earn a Walk-N-Roll t-shirt, $250 to earn a SBAGNE-branded tote bag, and $500 to earn a SBAGNE-branded bluetooth speaker. Visit our fundraising page to set up your fundraising team or to donate to an existing team.

Register for BEST

BEST Weekend 2018 is scheduled for October 19-21 at Pappas Rehabilitation Hospital in Canton, MA. You can look forward to a pizza party, use of the basketball court and bowling alley, seminars for youth and parents, time with friends and much, much more. Online registration isn't up yet, but you can email Andrew Vacca at **avacca@SBAGreaterNE.org**.

BEST is a weekend away for teen and tween boys living with Spina Bifida (and a parent) filled with games, activities, sports, education, health conversations, social connections, and fun.

Join our Adult Group

Our Adult Group has two dinners coming up! Come eat, chat, and enjoy company with other adult members of the Spina Bifida community. Find us at Wahlburgers at the Hingham Shipyard in Hingham, MA on September 20th, and The Grill Next Door in Haverhill, MA on October 18th, both at 6:30pm.

Contact Laura Lambert at **llambert@SBAGreaterNE.org** for more details or to RSVP for the events.

Support our Falmouth Road Race team

Each year, SBAGNE constituents, friends, and supporters participate in the annual Falmouth Road Race. We have a fabulous team this year that is hard at work raising funds for SBAGNE. To support our team, visit our fundraising **page** and click DONATE.

The Falmouth Road Race has become a major fundraising avenue for SBAGNE and a great way for members of our community to connect and enjoy the summer heat! To learn about the Falmouth Road Race, visit the website **here**.

Summer Activities

There are plenty of great ways to enjoy the summer! Try out:

Accessible gardening
Play games, go swimming, do a service project
Join an adaptive athletic team
Grab a drink or take a tour at a local brewery

Back to School

Going back to school can be an adventure! Get your kids back to school or get ready for college:

Back-to-school tips for parents of children
Help your child with disabilities transition
Winning in college
Grants for students with disabilities

SBAGNE Circle of Strength

When you make a donation of $500 or more, you're philanthropic giving plays a critical role in shaping the future of SBAGNE. By making a commitment at this level, you lead by example and support the Spina Bifida Community. Your gift of $500 or more sustains and strengthens the work of SBAGNE.
Please join today.

Circle of Excellence
$10,000- $24,999
*Personalized Naming Opportunity
A unique, customized certificate recognizing your support
Invitation to be on SBAGNE Advisory Board
Name recognition on our Donor Wall
Name recognition on SBAGNE Annual Report
Subscription to SBAGNE Newsletter

Circle of Aspirations
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A unique, customized certificate recognizing your support
Invitation to be on SBAGNE Advisory Board
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Name recognition on SBAGNE Annual Report
Subscription to SBAGNE Newsletter

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Name recognition on SBAGNE Annual Report
Subscription to SBAGNE Newsletter
Window Decal

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$ 1000- $2499
Name recognition on SBAGNE Annual Report
Subscription to SBAGNE Newsletter
Window Decal

Circle of Promise
$ 500-$999
Name recognition on SBAGNE Annual Report
Subscription to SBAGNE Newsletter
SBAGNE Awareness Bracelet

*For more details in personalized naming opportunities, please contact **Andrew Vacca** at **avacca@SBAGreaterNE.org** or **888-479-1900**

Letter from the Executive Director

When I landed at the Phoenix airport a few weeks ago to attend the executive directors and leadership retreat sponsored by the SBA national office, I couldn't believe what I heard the flight attendant say. So, I pulled out my phone, and sure enough, the report that the outside temperature was 115 degrees Fahrenheit was accurate. I've never been so thankful for ain air-conditioned building as I was those few days.

A number of topics were covered during those meetings, and I had the opportunity to network with many of the other SB chapters represented. One topic that was discussed was really exciting to me and I'd like to share it with you. Over the last few years, volunteers, researchers, SB clinics, and doctors in coordination with the national SB office have been working on a project updating the health care guidelines for patients living with SB. There are 24 different guidelines will be released! They will be released electronically and completely free to access on the national SB website in an app-style format. We can help the effort distribute these guidelines out by downloading them and giving them to your local SB clinic, PCP or other healthcare provider. These guidelines will provide a resource for health care providers who may bot be familiar with SB a quick and easy resource to ensure patients with SB get the best possible care. We'll be looking into ways to best distribute them around the New England area and we'll be sure to let you know what we decide. Be on the watch for the release of these guidelines in October and help us get them into as many health care professionals as possible!

We are also fortunate to have several great state and national parls scattered across New England. You may have already spent some time this summer enjoying these parks. I know I have this summer!

The National Parks Service offers a lifetime pass for persons with disabilities called **The Access Pass**. For a nominal fee of $10, a person with a disability (regardless of age or level of disability) can obtain this pass and gain access to the 2,000 national parks across the contry free of charge. This is what the NPS website says about the pass: "The Access Pass is a free, lifetime pass available to United States citizens or pernament residents, regardless of age, that have a permanent disability. The Pass can be used at over 2,000 federal recreation sites across the nation, including national parks, national wildlife refuges, and many national Forest Lands." This pass also offers discounts (sometimes as much as 50%) on campground reservations and other amenities at national parks. I've taken advantage of the discount on camping several times across the country and plan to use this perk again on the Kancamangus Highway in northern New Hampshire before the summer comes to an end.

To obtain the Access Pass, you'll need to fill out the application, submit proof of residency and disability. The link is provided below. Wherever you live, it's probably near a state or national park. Consider taking advantage of the Access Pass and go explore the nature right ourside your door. Happy Exploring!

Andrew Vacca

Upcoming Events

Join SBAGNE at the Worcester Palladium

Anthonee Jose "AJ" Rivera is among the youngest boxing promoters in the United States. Last year, he and his father, retired champion, Jose Antonio, started their boxing promotion company, Rivera Promotions Entertainment.

AJ was born with spina bifida and has strong ties to central Massachusetts. As such, the father-son duo is including SBAGNE and the spina bifida community in the boxing bout scheduled for August 17th at the Worcester Palladium. Learn more about the event **here**.

Meet us at the Expo

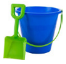
Meet SBAGNE at the Abilities Expo, Boston, September 21-23, 2018 at the Boston Convention & Exhibition Center, Hall A. The Expo will be open from 11 AM - 5 PM on September 21 and 22 and will be open from 11 AM - 4 PM on September 23. The Abilities Expo has been operating for nearly 40 years and is a major source of information for the disability community. The Expo includes a wide variety of interests like adaptive sports and dance, technology, mobility devices, workshops, and much more.

Registration for the Abilities Expo is free. To learn more, visit **https://www.abilities.com/boston/**.

Ways to support SBAGNE

Tour de South Shore

With the help and support of the Holleran family, SBAGNE is once again part of the annual Tour de South Shore, organized by the McCourt Foundation. Last year, Liam's Leadouts won the cup for highest fundraiser. To help the team defend the cup, join the team or donate to an existing team member. Learnn more about the Tour de South Shore.



Shop with Amazon Smile

Don't forget to use Amazon Smile for your online shopping! By shopping Amazon Smile and by making SBAGNE your non-profit of choice, you can support SBAGNE while continuing to ship through the same Amazon you know and love. Find out more by visiting **Amazon Smile**.

Find us on Social Media

We are present on Instagram and Twitter @SBAGreaterNE and on **Facebook** and **Pinterest**! To always get the latest information, photos, and updates follow us online.

Happy Summer!

All of us at SBAGNE would like to wish you a happy summer! To celebrate, we invite you to participate in a little friendly competition. We have hidden a tiny beach pail somewhere in this newsletter. The first three people to find it will receive a Starbucks gift card! Email Laura Lambert at **llambert@SBAGreaterNE.org** with the location of the beach pail to play.

Be empowered

You are invited to apply to our Empowerment Benefit Program. The benfit funds may be used for reimbursement for adaptive equipment, camp attendance, recreation and activities, adaptive sports and recreation equipment, urological supplies for individuals over the age of 3, durable medical equipment, and assistive technology. Currently, children and youth aged 18 and younger who are living with spina bifida are elibigble to apply.

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

We are now paperless

We have officially gone paperless! We consider this to be a great opportunity for us to improve our impact on the environment and to streamline our communications with you, our constituency. If you are not already on our e-mailing list, please email Laura Lambert at **llambert@SBAGreaterNE.org** so that we can make sure you receive our next newsletter electronically.

Applications are open

SBAGNE is now accepting applications for the 2018 Jean Driscoll Award. This $1,000 award may used for educational, developmental, or assistive programs or needs, and will be awarded to a SBAGNE constituent, age 14 or older, living with spina bifida who best demonstrates the character and determination of the scholarship's namesake.

To apply for this award or to find more information, visit **www.SBAGreaterNE.org** and click the heading, “Financial Services.”

This award is named after Jean Driscoll, an accomplished athlete and world-renowned speaker, who was born with spina bifida and has used a wheelchair since her early teenage years. Driscoll is a Paralympian who won silver medals in both the 1992 and 1996 Summer Games. She is a world record holder in the 10,000 meter track event, 10k, and marathon races. She also won the Boston Marathon eight times and is the only person in Boston's 105-year history to achieve this record.

Share your experiences with the SBAGNE Community

In each of our newsletters, we include articles from outside sources that can offer valuable insight and information. However, we know that we have experts, like you, right here in our greater New England community. That's why we are inviting you to submit an article to SBAGNE to be included in one of our upcoming newsletters. You can write about anything from your experiences with accessible travel, involvement in adaptive sports, building friendships, relationships, and connections while living with spina bifida, caregiving, parenting, adulting, and so much more. As constituents living with spina bifida, as caregivers, as medical professionals, and as family members, you are experts in your experiences and we hope you will consider sharing your experience and expertise with the rest of our community.

To submit an article to our newsletter, email it as a word document to Laura Lambert at **llambert@SBAGreaterNE.org**. If your article has been selected for a newsletter, we will let you know via email before sending out the newsletter.

SBA Leadership Week

In late July, our Executive Director, Andrew Vacca, went to Phoenix, AZ to attend the annual executive director retreat and leadership week. The retreat is an opportunity for Executive Directors from across the country to come together to exchange ideas, get updates from national, and learn from one another. Check out this **SB Insights article** to get the recap.

SBA National Updates

The national Spina Bifida Association has sent out the save the date for the next SBA advocacy event on Capitol Hill from May 13 - 15, 2019: TEAL ON THE HILL.

"Together, we can make our voices heard, advocating for policies to help ensure everyone with Spina Bifida has access to high quality, affordable health care. You have the power to make this happen and to educate lawmakers on the crucial issues affecting the lives of people with Spina Bifida."

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National is also compiling a list of shoes that work well with AFO's for children and adults. If you would like to add to their list, fill out this survey.

In the News

Summer Picnics

We enjoyed some summer fun in Maine and Massachusetts, picnicking at Green Hill Park in Worcester, MA on July 21st, and at the Maine Wildlife Park in Gray, ME on its rain date of August 5th. Together, we enjoyed sandwiches, snacks, and lawn games while building lasting friendships among children and adults. Thank you to everyone who participated and we look forward to seeing you again at future events like our annual holiday parties.

Massachusetts Walk-N-Roll

Thank you to everyone who participated in this year's Massachusetts Walk-N-Roll! It really felt like a party. We played music, met Ms. Wheelchair Massachusetts, ate pizza, made canvas art with water guns loaded with paint! And we still had time to Walk-N-Roll for Spina Bifida! Together, we raised $21,531!

Thank you to all of our participants, fundraisers, and donors for your support of SBAGNE. Thanks also, to Boston Children's Hospital for being a Silver Sponsor for the event. If you have not yet donated, you can visit the **FirstGiving page** and click "donate."

Spina-Beautiful's Story

This one isn't going to be easy to write and I'm sure not easy for you to read. It's my story, or at least part of it. It's the part of my life I chose to share during my recent Teal on the Hill trip to help raise awareness of poor healthcare for adults living with Spina Bifida.

The night before our meetings on Capitol Hill was a sleepless one for me. Believe it or not I hadn't really thought about what I would say to each of these people. I wasn't sure how I would feel spilling the beans to total strangers. During our first meeting I didn't really tell my story. I let Jennifer (the rep from Massachusetts) take the reigns. She talked a lot about being an adult with Spina Bifida and how the quality of care that she is receiving now is not as great as it was when she was a child.

You see, as children with Spina Bifida her and I both got amazing care (expensive, but amazing). We both were set up with regular visits at clinics in our home states. Because Spina Bifida really effects the whole body these clinics got a team of over a dozen different doctors together to work collaboratively for their patient. I remember going to my clinic at Dartmouth Medical Center in Lebanon, NH feeling really special. Like, all these people are here for ME! We were an awesome team! However, as adults, Jennifer and I both agree the quality of care is not the same.

There are 16 clinics for adults living with Spina Bifida in the US and none of them are in New England. My hope was that my story would raise awareness to the issue and hopefully bring more quality care to NH someday (or at least a little closer).

The Senators and state representatives weren't surprised to hear that we got quality care as children. It's very common in every state that a child with Spina Bifida go to one of these clinics. But, what happens when that child turns eighteen and doesn't live in one of the 16 states with an adult clinic? When, they were shocked to hear this.

MY STORY

When I turned eighteen I was told I was too old to keep going to the clinic in Lebanon, NH. I was told that they focus mostly on children since that is when kidney development is most crucial plus the clinic was shutting down completely due to a lack of funding. So I was left to find new doctors (with the help from my parents, of course) to hopefully be provided the same quality care I had been receiving. The unfortunate thing is a lot of doctors are not familiar with adults living with Spina Bifida. It isn't until recently that patients like myself are living as long as they do. We managed to find me decent care for regular visits and exams that helped battle the normal infections and preventative care. But...

Now fast forward to 2005. I had just graduated from college (21 years old) and found out I was pregnant (holy crap). Adimittedly not planned and not that excited about it at first, but I knew I was responsible enought and quickly fell in love with the idea of being a mommy! About 3 months into the pregnancy I started encountering some major problems. Basically my bladder and kidneys stopped working. Something was blocked by the baby's growth and urine was not able to get from my kidneys to my bladder. It is really bad (and not to mention painful) to have urine just sit in your kidneys. The only way to fix this the problem was to have two tubes (nephrostomy tubes) put in to each kidney through my back to release the build up of urine (gross). While this helped, it still didn't eliminate infections from coming and the (stupid) tubes would get blocked and have to be replaced over and over again. Long story short, I made it to month seven of the pregnancy only to be told during a routine checkup for the baby that there was not heartbeat. The news was devastating. I couldn't believe that after all I had been through I wasn't going to have this beautiful little boy to show for it. To make it all seem worthwhile.

Through this whole ordeal I really wished I had my team of doctors. The care during my pregnancy was so disjointed and unorganized. Non of my doctors really talked to each other and I was prescribed so many different things. Sometimes I felt like it wasn't even really clear as to whom I should call with an issue. If I had a more coordinated care maybe things could've been different. I can't help but wonder.

So there you have it - my story. It certainly caught their attention and had them shocked at the kind of care I had received during my pregnancy. I left my meetings feeling like I had raised more awareness for adult women living with Spina Bifida which was our mission. I left feeling like I could conquer the world!

By the way, his name is Xavier William Lovering-Lopez. He was born on November 3, 2005. I only got to hold him for a little while but he is forever in my heart. He made me a stronger woman and for that I am grateful. I know that everything happens for a reason and I have made peace with this chapter in my life. I tell Xavier's story not for sympathy but to help raise awareness for this very subject. It is so important to me that Xavier be my drive behind this whole blog. That his name not go unnotived but is heard where ever necessary in hopes that another woman with Spina Bifida does not have to go through the same thing. He was born into this world this way for a reason and I think I have finally figured out why!

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This article is reprinted from the blog Living Spina-Beautiful. The blog, written and monitored by Kristin Marquis, is built around empowering people living with disabilities. Read about Kristin below.

I was born with Spina Bifida and it was a BIG surprise to my parents! My mother had a perfectly healthy pregnancy with no warnings. I'm sure you can imagine their surprise when the doctors whisked me away as soon as I entered the world! It must be a lot like thinking you're landing on a tropical island for the best vacation of your life and then the plane lands and you see volcanos, it's freezing cold; total chaos. Well, good luck...you have to stay and make due.

I'm still navigating life with Spina Bifida and it certainly has it's ups and downs. I believe I wouldn't be deal something I can't handle, and this just makes me a stronger woman...It makes me Spina-Beautiful!

To check out her blog go to **https://spina-beautiful.com**.

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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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