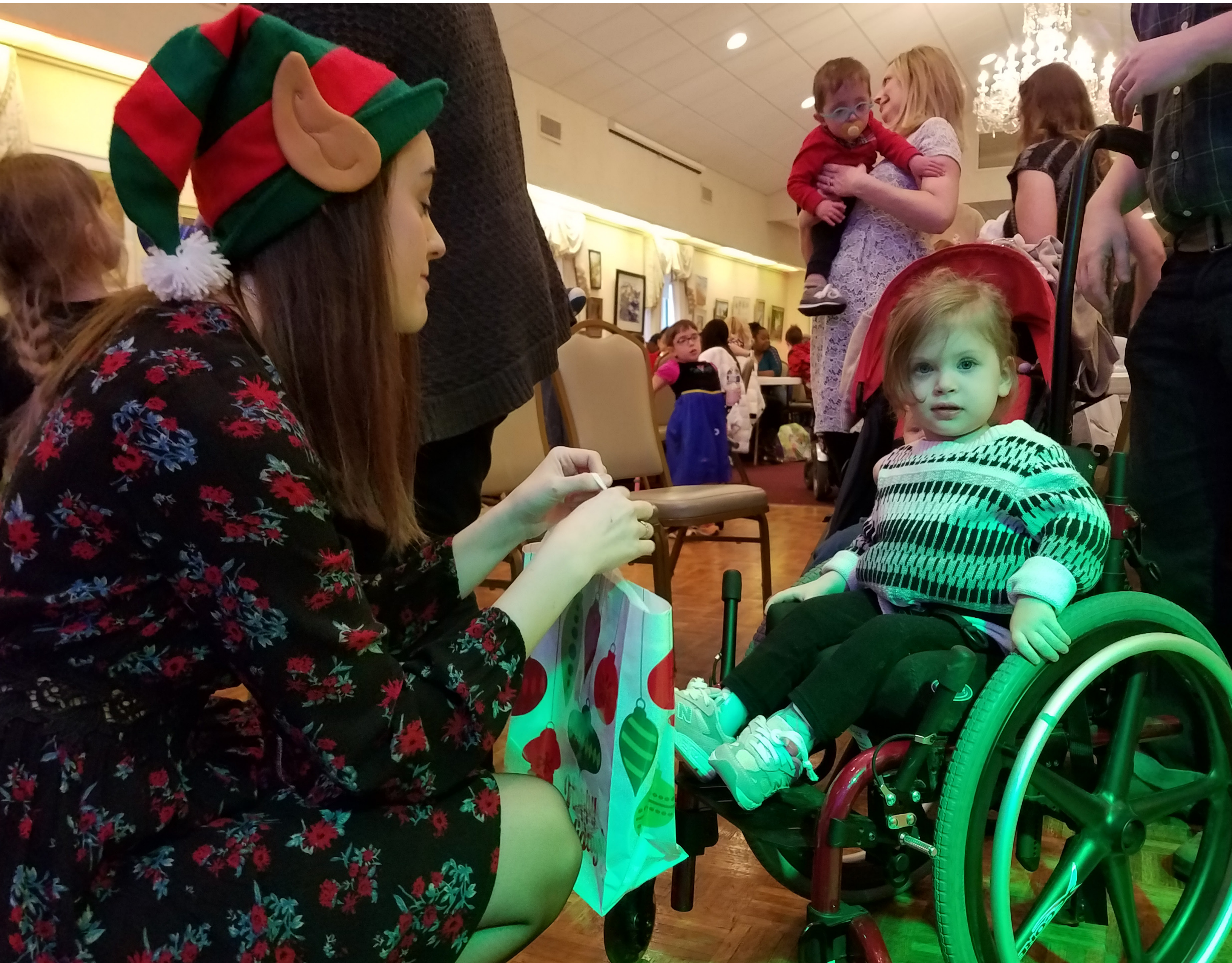
Winter 2018

SBAGNE news

SBAGNE Celebrates the Holidays

in Maine and Massachusetts



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

Walk-N-Roll TBA

Stay tuned for information about this year's Walk-N-Roll, projected to take place in June. We will send updates through our monthly email. You can also watch our website, www.SBAGreaterNE.org for details.

Waiting list for BLIN'G

BLIN'G Weekend 2018 is scheduled for March 2-4 at the Newton Marriott in Newton, MA. We are excited to announce that reiki massage and makeovers will be included in the weekend's activities. Spaces for the weekend are fully booked, however, if you would like to be added to the waiting list, please email Andrew Vacca at **avacca@SBAGreaterNE.org**.

BLIN'G (Better Living 'N Girls) is a weekend away for teen and tween girls living with Spina Bifida (and a parent) filled with games, activities, glam, education, health conversations, social connections, and fun for all.

This event is supported by the Constance O. Putnam Foundation.

Join our Adult Group this March

Our Adult Group will be celebrating adaptive sports by viewing the Winter Paralympic Games at Parlor Sports Bar in Somerville, MA. Watch emails and social media for the exact date and time which will be announced soon!

Contact Laura Lambert at **llambert@SBAGreaterNE.org** for more details or to RSVP for the event. Continue checking our monthly emails, website, and social media to learn about more Adult Group events and activities.

Run with us in the annual Falmouth Road Race

Each year, SBAGNE constituents, friends, and supporters participate in the annual Falmouth Road Race. As in past years, we have received 25 bibs. Our team is assembling quickly, so if you would like to become part of our 2018 team, please email Laura Lambert at **llambert@SBAGreaterNE.org**. This year, the race will take place on Sunday, August 19th and the fundraising minimum will be $1,000 per runner. 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 Picnics TBA

We are working hard to schedule our annual Summer Picnics. These familiy-friendly social events usually take place in Maine and Massachusetts during the month of July. Keep an eye on our monthly emails, social media, website, and subsequent newsletters for dates, times, and details.

Thank You

If you live near Lynn, MA, stop in and say a big thank you to the T-Stop Superette on Walnut Street for raising funds in support of SBAGNE! We would like to thank the staff for thoughtfully putting a cannister in their store to raise funds for SBAGNE. We also extend our gratitude to all the customers and staff members for their generous donations.

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.

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SBAGNE Awareness Bracelet

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

SBAGNE

Letter from the Executive Director

When starting any new position, personal connections can ease the transition. What has made becoming SBAGNE's Executive Director a smoother transition for me are the connections I made at our events over the past few months. From playing wheelchair basketball at BEST, hanging out with some really cool kids with Santa at our holiday parties, to planning for an awesome BLIN'G Weekend, it's the personal connections that have made this a wonderful start for me in this role.

Moving forward, the board and I will be looking at the existing programs we currently run and making sure they are the best they can possibly be for you to enjoy. We'll also look at new ideas for programming for adults and also look at partnerships with other agencies and organizations to grow and strengthen SBAGNE.

What I enjoy most is getting the chance to have a conversation with the members and families of SBAGNE about how we can make this association even better and stronger. If you have any ideas for future programming or ideas on existing programming, please feel free to reach out via email or phone and I'd very much enjoy the opportunity to talk. I'm looking forward to meeting as many of you as I can over the next few months at our upcoming events.

One of the hightlights of this newsletter is accessible travel. As an avid traveler, myself, I can attest to the excitement that comes with visiting new locales. Traveling to new places is always an adventure, and traveling to familiar places can be just as much of an adventure. My wife, Sarah, and I had the opportunity to travel to Europe to visit her grandparents for the holidays. Sarah's grandparents live outside of London, England and it's a very familiar place to us. We've been their a few times over the last ten years and it was comforting to know the little bakery with the delicious scones is still there on the corner of the town square.

When we're there, we know where to go and what to do; it's a familiar feeling which leads to more adventure. We use the town as a home base and go off to explore London and beyond. One of those beyond places was Vienna, Austria. During the holiday season, Vienna, like other cities in Europe, is known for its Christmas markets, and that was the draw for us. These outdoor markets are usually set up in the town square with hundreds of vendors selling handmade gifts, clothing, food, and drinks. These markets have been a staple during the holiday season for many years and make you feel like you're in a wintery fairytale.

Over the last few years, many European cities have taken major strides to become more accessible to those with disabilities. Most cities have a "visitor with disabilities page" on their websites that details things like accessible accessible public transportation, museums, and tourist attractions. Websites like these and other travel websites geared towards disabilities are great tools to utilize when traveling. Traveling with a disability can be a challenge, but with careful planning, a good travel partner (in my case a great one!) and an adventurous spirit, you can expect to see the sites the world has to offer and enjoy every minute of it. Happy traveling!

Andrew Vacca

Board Welcome

It is with great pleasure that we welcome three new members to the SBAGNE Board of Directors, each providing our community with a unique perspective and strengths that will support our mission and enhance our efforts to serve our constituents.

Robert Burke, MD, is a retired primary care pediatrician from Hasbro Children's Hospital in Providence, RI, where he specialized in children with special health care needs. He was the director of the spina bifida program and built a patient and family support group in his time at Hasbro. Dr. Burke comes to us with over 35-years of experience in caring for children with physical and developmental disabilities and those with special needs and complex conditions. We are thrilled that he is offering his knowledge and expertise in care of individuals with spina bifida to help guide our organization as a board member.

Santara Sen brings 5-years of experience as a board member for the Ms. Wheelchair of Massachusetts Foundation, including service as Board President for part of that time. She has also served as a mentor for disability organizations such as partners for Youth with Disabilities (PYD) and Easter Seals Massachusetts. As an individual living with SB, Santara has attended and assisted with numerous SBAGNE events since 2010. She is delighted to bring her board experience and her passion for SBAGNE to a role that will help her serve her fellow constituents and "give back" to the spina bifida community.

Dan Holleran is a career sales executive and the father of a young son with spina bifida. He has professional experience in financial planning, new revenue attainment and budget management as well as non-profit experience working with The Room to Dream Foundation and The McCourt Foundation. In 2016, he and his family raised $25,000 for SBAGNE in their own, private fundraiser. We are fortunate to have such a dedicated and hard-working member of our community joining our board.

Lastly, we are excited to welcome back Brendan Sullivan, who previously served on the board from 2001-2009 as board member, Chair and Treasurer. Brendan brings professional experience in leadership roles as Senior Associate Director of Athletivs and Chief Operating Officer for Holy Cross College athletics, and previously, as Director of Athletics at Stonehill College. We are fortunate that Bendan has agreed to use his experience managing large budgets at both these institutions to serve as Treasurer for SBAGNE once again! He also believes that, as an individual living with spina bifida, he can offer perspective and input from his personal experience to the organization.

Once again, we would like to offer a warm welcome to Dr. Robert Burke, Santara Sen, Dan Holleran, and Brendan Sullivan!

Ginny Briggs

Happy Valentine's Day!

All of us at SBAGNE would like to wish you a very Happy Valentine's Day! To celebrate, we invite you to participate in a little friendly competition. We have hidden a tiny heart 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 heart 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 going paperless

This will be our last paper newsletter. Starting this spring, we will send our newsletter entirely electronically. 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 spring 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.

Fill out the survey

Help the national Spina Bifida Association plan for the future! The SBA is seeking participants to fill out a brief survey about the SBA in advance of their March Board Meeting. The information from the survey will help the SBA plan its next steps for the organization. Fill out the survey **here**.

Save the date

The national Spina Bifida Association invites you to join the SBA's first ever advocacy event on Capitol Hill from May 8 - 10, 2018: 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."

TEAL ON THE HILL will take place May 8 - 10 and costs $75 per person. Please contact Sheliah Roy, Director of Marketing & Communications for the Spina Bifida Association at **sroy@sbaa.org** or 202-618-4743 with questions or interest.

This event is open to the entire Spina Bifida Community.

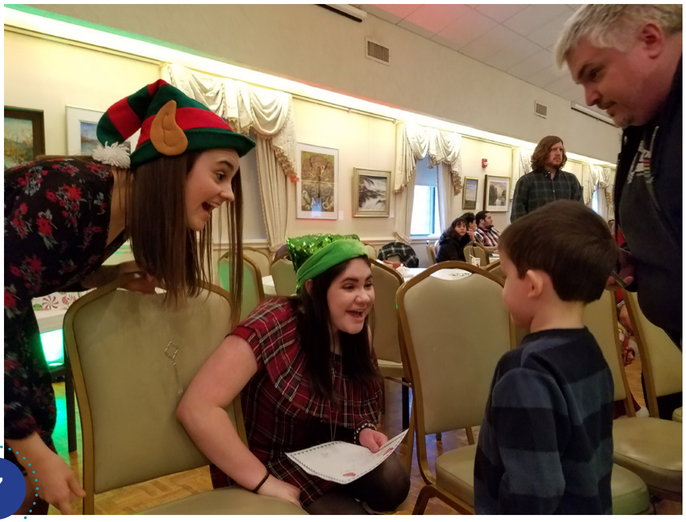
In the News

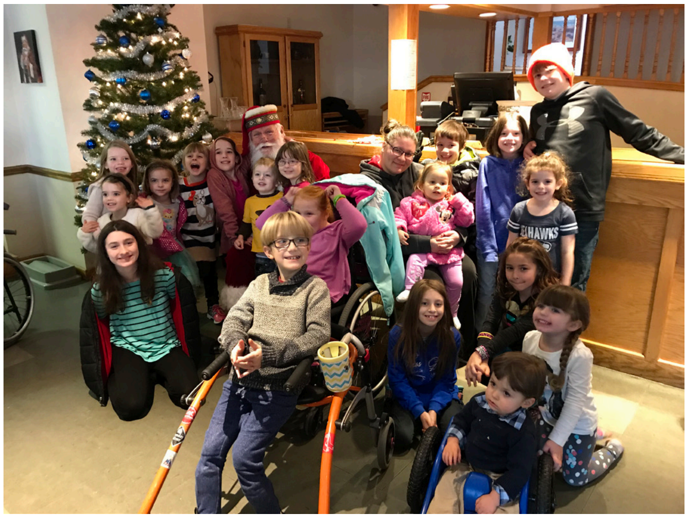
Lunar New Year Celebrations

A small group of SBAGNE Adult Group members attended the recent Lunar New Year celebrations at the Museum of Fine Arts, Boston. The event included dances, musical presentations, and martial arts demonstrations. The rest of the museum was also open to the public during the event, making it a great day to get out and enjoy one of Boston's gems. Be on the lookout for more Adult Group events you can attend, like the upcoming Paralympics Viewing Party.

Holiday Parties

SBAGNE enjoyed an extended holiday season, with parties on December 12, 2017, in Massachusetts and on January 21, 2018, in Maine. Both parties were successes! Kids loved getting gifts from Santa and his elves and everyone had fun socializing over lunch, taking pictures in the photo corner, and participating in raffles and yankee swaps. Thank you to all of our participants, volunteers, and supporters. Happy Holidays, everyone!





How to Overcome the Fear of Wheelchair Travel

*Originally posted on December 13, 2016 by Sylvia Longmire

Navigating the airport. Boarding the plane. Finding an accessible bathroom. Getting into taxis. Finding a hotel room that meets my needs. Cobblestones and no curb cuts. Steps and stairs.

Suggest an international voyage to a person in a wheelchair (or other mobility device), and the list of obstacles above often starts a chant in his/her head. Many wheelchair users have never left their home states, let alone their home countries. Sometimes it's a matter of expense or medical logistics, which can be very difficult to overcome. But sometimes it's just a matter of fear. Fear of getting hurt, fear of getting lost, fear of not being able to get help. . . fear of the unknown. But fortunately for you, my intrepid would-be adventurers, fear IS something that can be overcome.

Before you start reading my list of steps you can take to overcome this fear, there are some things you should know about me. First of all, I am a veteran, so I approach challenges with tactics and a battle plan. Second of all, I'm a control freak so I feel more secure when I have the most information possible. Hopefully, the combination of these two things will emerge in my list and help you overcome your own fears of traveling in your wheelchair.

1. Research, research, research. Knowledge is power. I can't emphasize enough how important it is to find out as much as humanly possible about your potential destination. Yes, it is unfortunate that we have to do so much homework as wheelchair users about the accessibility of destinations around the world. But it's a small price to pay in order to feel safe and comfortable in some of the world's most beautiful places. Google will become your best friend. Read blogs; read travel forums; read reviews. Find the accessibility sites for your destination's municipal government.

2. Practice makes perfect! While it's tough to practice boarding a plane, there are likely some places near you where you can practice getting in a cab, for instance. Or getting on a bus or a local tram or train system. Of course, accessibility is going to vary from US city to US city, and certainly between countries. But you can start to challenge yourself in a safe place. Go to an area of your town where you can practice navigating over rough sidewalks, or have your companion figure out how to help you deal with a sidewalk with no curb cut. Spend the night in an inexpensive local hotel so you can practice using an accessible tub or roll in shower. Try visiting new restaurants and shops, particularly ones that may be older, so you can figure out how to navigate things like tight spaces or smaller bathrooms. Push your equipment - and your courage - to the limit so you know what you're capable of doing.

3. Consider spending more for expert assistance. There are many tour companies out there that specialize in disabled travel - like mine at Spin the Globe / travel! They can offer everything from wheelchair accessible tours to transfers between airports, ports, and hotels, hotel and cruise reservations, and complete tour packages for groups. However, these services often don't come cheap. Not everyone can afford them, but if you have the budget, sometimes it's worth it to let somebody else worry about making all the accessible arrangements for you in a new place.

4. Insure EVERYTHING. Before I started traveling with my electric scooter, I never got travel insurance for anything. I thought it was a complete waste of money and just some kind of scam. However, now that I have multiple sclerosis and their is a much greater chance that something might happen to me physically to prevent travel unexpectedly, I insure absolutely everything, from plane tickets to cruises. One of my biggest fears is that I will get sick or hurt abroad, especially when traveling alone, which I do often. Having travel insurance gives me peace of mind that I won't become penniless if I have to be hospitalized or otherwise cared for in another country. It goes without saying that your wheelchair and/or other medical equipment should be insured in the unlikely scenario that it gets damaged en route to your destination.

5. Accept that not everything will go as planned. I will be ther first one to admit that this is the hardest thing for me when I travel (see control freak mention above). I'm not a big fan of change, the unexpected, or short-notice anything. However, there are some things you can't just plan for when it comes to travel. This is why it is cruicial to have a positive attitude. Instead of saying to yourself, "I can't do this!" ask yourself, "How CAN I do this?"

6. Be flexible. This is more or less a continuance of number five above. Your success in being flexibile has a lot to do with your personality, your comfort zone, and your sense of personal space. For example, I'm a HUGE fan of helicopter tours. They are definitely not the most wheelchair accessible things around. But if someone has to pick me up and throw me over their shoulder to toss me into a helicopter in order for me to land on a glacier somewhere, I'm perfectly willing to let somebody do that. Not everyone feels comfortable with being picked up and transfered by a total stranger. But if your priority is to get somewhere and see something amazing, try reconsidering your boundaries.

7. Increase your confidence through experience. I used to think that I was addicted to just travel. Then I noticed a trend in my travel choices. With every trip, I become a little more brave. I'm picking places where English is not the primary language, or where I have to rely more on public transportation than accessible taxis. I have become addicted to the rush of overcoming my fears through experience. The more you travel, the more confident you will become for future travels. The blogs of other wheelchair using travelers will be on your browser's favorites list. You will know Metro system layouts like the back of your hand before you ever arrive in a city. You will learn exactly how to ask for the type of hotel room you want while talking to ever arrive in a city. You will learn exactly how to ask for the type of hotel room you want while talking to someone who isn't exactly sure what "accessible" means. And most importantly, you will learn what your hard limits are, and when you can challenge yourself to do more.

8. Have faith in humanity. I consider myself to be a pretty cynical person, but there has been no better cure for that than my travels. I am continually surprised by the almost unlimited kindness of strangers in almost every corner of the world. Of course, you will come across cultures and people who don't really know what to do with us, but they are largely the minority. Ask for help if you need it, and 99 times out of 100, people will bend over backwards to make you feel included and get you where you need to go.

I really hope this eight step guide can encourage you to step outside of your comfort zone and explore some of the amazing accessible spaces this world has to offer!

*Sylvia Longmire is a service-disabled veteran, travel consultant, world traveler, and Spin the Globe creator. To visit her blog, go to **www.spintheglobe.net**.

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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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