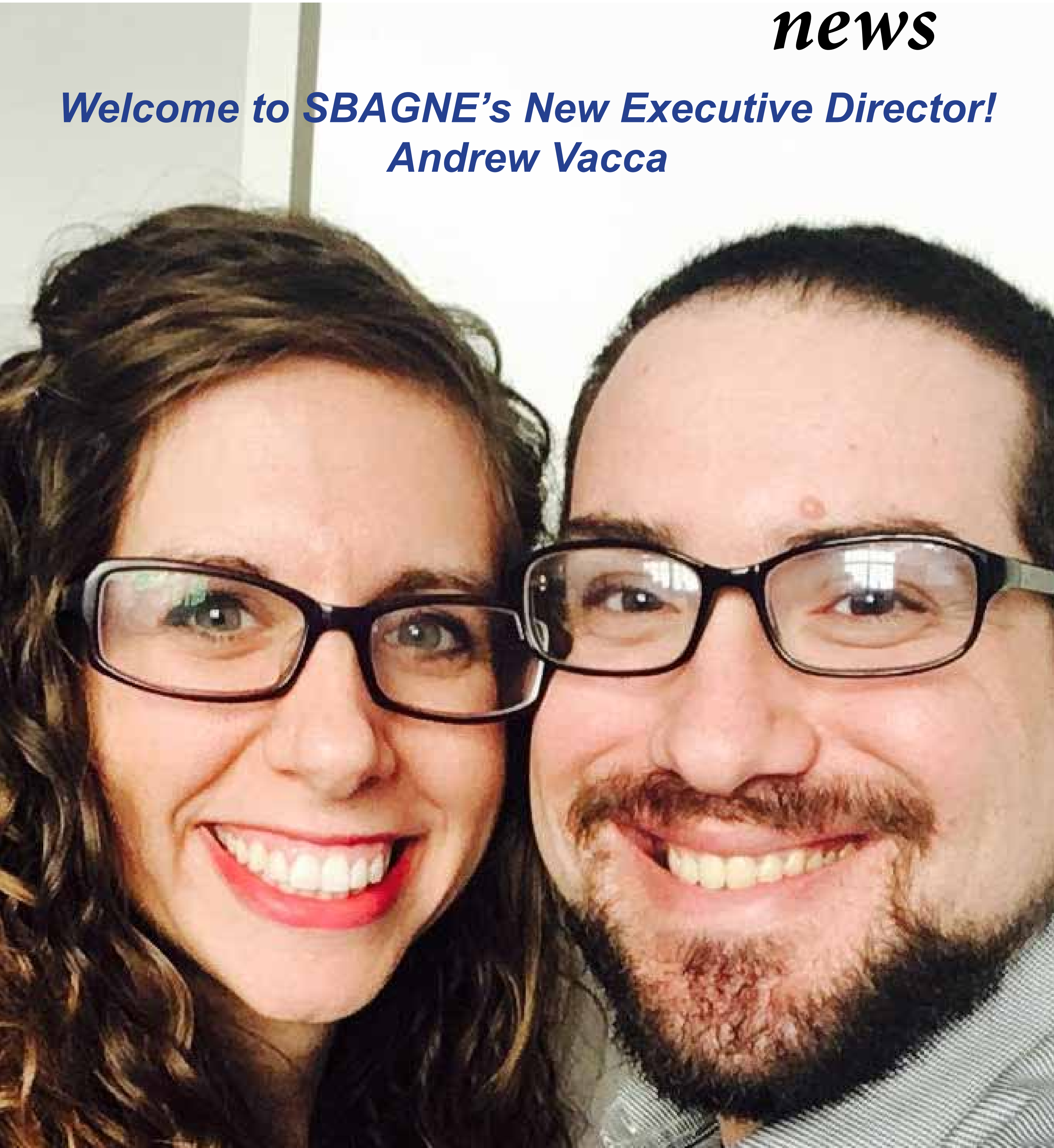
Summer 2017

SBAGNE news

Welcome to SBAGNE's New Executive Director!
Andrew Vacca



SBAGNE
news

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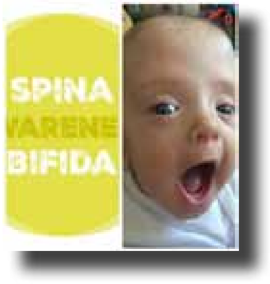
SBAGNE is a group of parents, adults and children with Spina Bifida and dedicated professionals working together to support and encourage families and individuals throughout the Greater New England area. It is our goal to enrich the lives of those affected by Spina Bifida through education, parental 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

McCourt Foundation Tour de South Shore



Join Team "Liam's Lead Outs" for a 20 or 50 mile ride around the South Shore on September 23rd. Usher in Spina Bifida Awareness Month, raise awareness and support SBAGNE. Visit **www.SBAGreaterNE.org** for more information.

BEST 2017 - 5th Annual Weekend

JOIN SBAGNE and Boston-Children's Hospital, Center for Spina Bifida and Spinal Cord Conditions

BEST (Boys, Success, Esteem, and Training) Weekend will include *two* night stay at the hotel, educational seminars about healthy living, nutrition and athletics.

When: October 13-15,2017

Where: Homewood Suites, Canton, Ma; All Activities will be held at Pappas Rehabilitation Hospital for Children, Canton (formerly Mass Hospital School)

Who: 10 Boys (ages 10-16) living with Spina Bifida and one parent
(Space is limited to 15 boys and a parent. A waiting list will be available)
Cost: $25.00 per parent/son

RSVP: By October 6, 2017 at SBAGreaterNE.org

New England Spina Bifida Conference

A Conference for Families, Adults, Health Care Professionals and Educators
Saturday, October 21, 2017

SERESC Conference Center, Bedford, NH

Watch **SBAGreaterNE.org** for registration information.

Letter from the Executive Director

This is my last letter as Executive Director. After 12 years with SBAGNE I am retiring and moving on to the next adventures in my life. I will be a year-round resident on Cape Cod, my feet in the sand with an enjoyable book.

Connection is defined by Brene Brown, author, speaker and researcher, "as the energy that exists between people when they feel seen, heard, and valued; when they can give, and receive without judgment; and when they derive sustenance and strength from the relationship." I hope in my time with SBAGNE I hope I have fostered the development of connections within the Spina Bifida Community. The support of everyone I have met, worked or volunteered with, have made my work with SBAGNE enjoyable and easier. I value the many connections I have made during my tenure with SBAGNE and will sincerely miss those I have come to know and consider friends.

Please welcome **Andrew Vacca** as the new Executive Director with SBA of Greater New England. Andrew is excited to join SBAGNE. I feel confident that Andrew will be an excellent addition to SBAGNE and will ably lead the organization. I am looking forward to working with Andrew during the transition.

Upcoming opportunities to develop and build on friendships are many. BEST (Boys, Esteem, Success and Training) is planned for October 13-15th; New England Regional Conference is scheduled for October 21st in Bedford, NH and watch your email for dates and locations for the 2017 Holiday Parties as well as adult events.

Thank you for allowing me to serve as your Executive Director.

Ellen

Introducing Andrew Vacca

New SBAGNE Executive Director

As an adult living with Spina Bifida, I understand the unique victories and challenges associated with the condition. I was born in Westerly, Rhode Island and spent the first six months of my life in Rhode Island Hospital. After graduating from college in Central Florida, I began volunteering and working with disability non-profits. I served two terms on the board of directors with the Spina Bifida Association of Central Florida from 2010-2016. I also joined the staff of Lift Disability Network in the Fall of 2012 as a Program Coordinator. While with Lift, I created a monthly respite program for families with various disabilities and served on the leadership team for Lift's annual summer camp. I also facilitated and led disability awareness and etiquette training courses, and volunteered with many disability non-profits in the Central Florida area.

My wife Sarah and I moved the Greater Boston area in the Summer of 2016 and are enjoying being back in New England. Sarah works in project management with a clinical research organization in Boston. Together we enjoy cooking, camping and traveling, having visited 12 countries together with more planned for the near future.

I am extremely excited to be named as the new Executive Director for SBAGNE and looks forward to serving the many wonderful families in New England.

Andrew

Grace Anne Lenz - Jeanne Driscoll Awardee

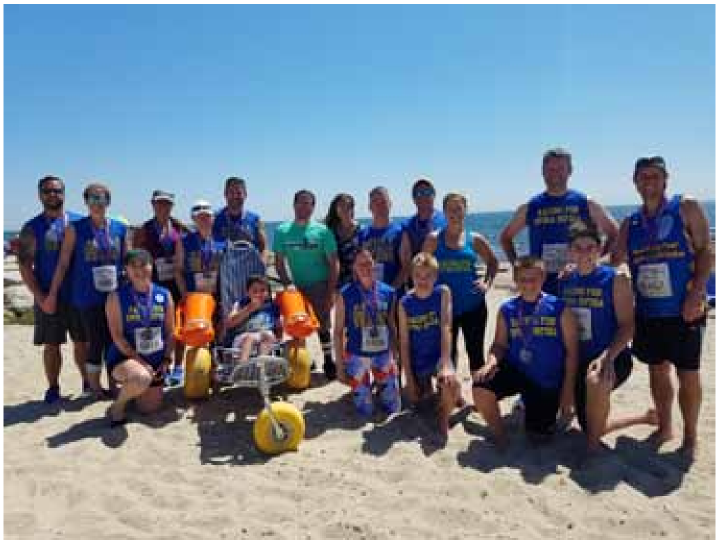
Hello my name is Grace-Anne and I was born with spina bifida and hydrocephalus and 18 years later nothing has gotten in my way. I will be graduating High School in June and I will be attending Bristol Community College. Living with spina bifida and hydrocephalus has had its ups and down's, but I have learned not to let it get to me and that I can accomplish anything I put my mind to. One of the major passions I have for my future is becoming a nurse. I want to help children with disabilities similar to mine and those that have had a rough start to their lives. Without all the hospital stays and doctor's visits I do not think I would be pursuing the occupation of nursing. My fascination with medical/doctor television shows was also a huge help in my decision of becoming a nurse. As a child all I would watch was the Discovery Channel. My favorites were the shows where babies were born. Also the ER medical shows. My parents would be like "Why are you watching that?" I would respond with "because it is interesting to see". The medical field has always been a part of my life due to the spina bifida and has given me life experience that most people cant imagine. I believe it is time that I need to give back, use my experience in a positive way and start helping out those in need like those who have helped me.

Even graduating high school has been a huge goal in my life. The doctors, ever since I was a baby, had told my parents that I would never graduate high school, that "perhaps" I might qualify for a certificate and I would need "this and that" to accomplish school but here I am, 18 years later just a few days from graduated with a full diploma and headed to college. Without my parent's support with my decisions I have had throughout my life, I do not think I would be in the position I am in today. I truly believe that I am no different than anyone else in this world that we live in and don't judge a person by what you see.

In the News

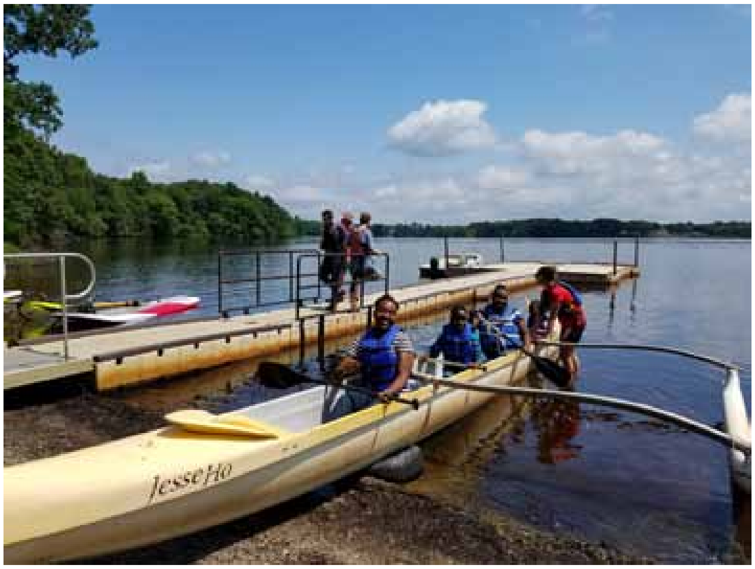
Falmouth Road Race

This year's Falmouth Road Race was a huge success! By race day, August 20, SBAGNE's 24 participants were able to raise more than $40,000, well above our initial goal of $35,000. Our racers braved summer heat, sun, and hills to join the 11,026 finishers in the 7 mile race. We recovered during the annual after-party at Bristol Beach by relaxing on the sand, drinking lots of power drinks, and catching up with old and new friends. The 2017 SBAGNE team was a perfect mix of veteran runners and first-year participants, and new runners are always welcome to apply. Keep an eye out for news in the new year if you would like to run with us in 2018.



Summer Picnics

This past July and August, summer-loving families braved the overcast skies to attend our annual summer picnics in Maine and Massachusetts. The gatherings were full of fun perks like door prizes and pontoon boat rides. Some attendees even got the chance to try out canoeing! Swimming and sandwiches may have been the initial draws, but the camaraderie and fellowship between seasoned constituents and families new to our community were even more valuable.



Walk-N-Roll a Great Success! Thank You!

I'd like to thank each of you who walked this year in the 2017 Walk-N-Roll on behalf of SBAGNE. Not only did we meet our fundraising goal, we surpassed it by a large margin! Way to go! We'll see you next year!

Andrew

Exposure and Experience

by Kathie Snow, www.disabilityisnatural.com

How often do we presume a child or adult with a disability is incapable, incompetent, unable to learn, and so forth? Have we considered that perhaps the person has had no exposure to or experience with the situation?

"Sara" talked to me about her son with a disability,"Tommy," describing how far behind he was compared to his brother and other children (without disabilities). During our conversation, it became apparent that Tommy had not had the same *opportunities* as his brother or other children. Because Tommy spent his life in segregated, self-contained environments at school and in special sports activities, he did not have *exposure to and experience with* education in a general ed classroom, as well as ordinary age-appropriate and inclusive community, social, or recreational activities. Tommy hadn't learned how to: get along in the real world, make decisions, be responsible, make friends, be safe, or a myriad of other typical skills that are *routine* for children *without* disabilities.

> **He displayed the physical characteristics of Down syndrome so just one look at his face and everyone knew there was no point in sending the boy to school. It's true he was a slow learner but that might have been because nobody ever tried to teach him anything.**
>
> *Colin Cotterill in*
> Disco for the Departed

This lack of exposure and experience during Tommy's childhood will, in general, cause him to be ill-equipped for a successful life as an adult. He will have learned only how to survive in self-contained, segregated environments. And instead of looking at what *we* did or didn't do, we (Tommy's family members, teachers, professionals, and/or others in his life) effectively "blame the victim:" Tommy can't (do-this-or-that) because he has (type of disability).

Consider the example of orphanages in some Eastern European countries where very young children were left untended by staff. Because of the lack of human interaction, the children were diagnosed with "failure to thrive." They were denied the normal opportunities that promote growth and development; they were products of their environment. *And all of us are products of our environment.*

The philosopher Ivan Illich wrote, "Most learning is not the result of instruction. It is rather the result of unhampered participation in a meaningful setting." Think about it: "unhampered participation" and "meaningful setting"— do those descriptors fit what happens to most children or adults with developmental disabilities? Not really. Most don't experience "unhampered participation" in any setting; their lives are circumscribed by plans, rules, schedules, consequences, helpers, etc. You may believe that a child being in a self-contained classroom or an adult in a day program/workshop *does* represent a "meaningful setting." But in comparison to what? If all you've ever had is vanilla ice cream, you think it's the best! You might feel differently after visiting a 31 Flavors ice cream shop.

The opportunities available to children and adults with disabilities are not limited by *their diagnoses,* but by *our attitudes and actions.* We put limits on them because we've put limits on our imaginations! We're hampered by the status quo, conventional wisdom, standard practices, etc.; we tend to do what's always been done. We're stuck. And the consequences to the children and adults with disabilities in our lives are incalculable.

Let's think about choices. When I was a child, I had a list of "what I wanted to be" when I grew up. But I've never done any of those things! Why? Because as I matured, I had experiences that taught me about jobs I didn't even know existed. Back in the late 1970s, I was a secretary at a local TV station. It was an incredibly exciting new world of producers and camera operators and film editors and technical directors of the local news shows. And, boy-oh-boy, I thought being a director would be a fun job! I asked my boss about the possibility. He thought it was a ridiculous idea and was very discouraging. First, he told me, I was "a girl" (I was 26) and females didn't do jobs "like that." Second, I couldn't be a director until I could operate a studio camera, adjust lights, build sets, and much more. But I was determined and I applied for the next "studio tech" opening. I got the job and took a cut in my already low pay. Then I worked hard, learned much, and *did* become a director (one of the first female directors in the state of Texas I was later told).

> **You are what you learn... A person changes at a fundamental level as he or she merges with a particular field of knowledge. If you don't like who you are, you have the option of learning until you become someone else. There's almost nothing you can't learn your way out of. Life is like a jail with an unlocked, heavy door. You're free the minute you realize the door will open if you simply lean into it.**
>
> *Scott Adams*

It took exposure to and experience with TV production to make it happen. Growing up, neither myself or my family, nor anyone who knew me, ever considered I'd enjoy a career in television. It was possible because my parents and teachers didn't put limits on me; I was free to try this-and-that—to explore and make choices about my life. My situation is not unique; most adults (without disabilities) have enjoyed a lifetime of making choices that have led to exposure to and experience with new situations.

Some of the choices we made didn't turn out as well as we thought, right? "It seemed like a good idea at the time..." And most of us learned a great deal from our screw-ups; our failures are usually more instructive than our successes. Children and adults with disabilities need the same opportunities to explore, discover, succeed, fail, etc.—to learn!

What will it take for us to ensure children and adults with developmental disabilities are participating in ordinary experiences that promote personal growth? What are the barriers? The answers are flip sides of the same coin.

First, focus on the person's strengths and abilities, not the diagnosis or "problems." Then your mind will be open to possibilities. If, for example, you feel that, "Helena will never be able to (fill-in-the-blank)..." *You're right!* Helena will *not* be successful—not because she has a disability but because of *your attitude!* If, however, you see her abilities and strengths (and ensure others also focus on those traits), and if you also ponder *how* Helena can be successful, you'll figure out what supports, accommodations, assistive technology, etc., she needs to make it work. Add in some big dollops of patience as necessary!

Next, minimize your fears and maximize your hopes. We may inadvertently put limits on people with disabilities because of our fears: the person might fail or embarrass himself or us; others might not like or understand the person; it's asking "too much" for others to include/welcome a person with a disability; and the list goes on and on. We cannot allow *our* fears/emotions to limit another's opportunities. Embrace hope and trust in the kindness of strangers.

Finally, expect success and support failure. If your first efforts don't work, try again! Learn from the experience and value the lessons learned; commiserate with the person instead of criticizing (and share some of *your* failures). Brainstorm how or what to do differently next time.

Throughout, we need to be listening to the person with a disability. What is the person interested in doing? What would be relevant and meaningful to him/her? Be on the look-out for opportunities and share your ideas with the person.

Your enthusiasm and excitement will rub off on the person. And there's no doubt you'll run into a "no" sometimes, but don't take it personally—this is not about you! See a "no" as a positive: the person is speaking up and self-advocating! (You want your wishes to be respected when you say "no"—treat others the way you want to be treated.) Open the door to opportunities; exposure and experience can enrich a person's life forever!

See these related articles:

"Environment, Environment, Environment"
www.disabilityisnatural.com/environment.html

"Permission to Fail...and Succeed"
www.disabilityisnatural.com/permission-to-fail.html

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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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