SBAGNE news

Winter 2013 The Newsletter of the Spina Bifida Association of Greater New England

SBAGNE

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YEARS

1971-2013

Notes from the Chair

by Matt Neal

Obligatory Seasonal Reference

Ok, it's not obligatory. These are my notes and I can say whatever I want. Still, it is typical for something written once per season. Especially for me I see, as I look back on previous posts. I shall now transform typical into traditional. To wit: It was really cold a couple of weeks ago! Here we are on the other side of that now, albeit somewhat the worse for the wear and tear (that last bit is one of my favorite quotes, it's from Beatrix Potter, *Peter Rabbit*). My point is that was probably the worst of it. So if you deal with winter by doggedly hanging in there until spring, it's working! There's a way to go yet, but the darkness is retreating a little bit every day. On the other hand, if you deal with winter by getting out there and digging it then I have two things to say to you: 1) get busy, winter will be over before you know it, and 2) did you know that Spaulding Adaptive Sports Center offers adaptive skiing events of both the Nordic and Alpine variety? They do it collaboration with their partners New England Disabled Sports for alpine skiing at Loon Mountain and the New England Nordic Ski Association for cross-country skiing at the Weston (MA) Ski Track. There is also rock climbing if you want to be both active and indoors. These special events happen on certain days in February and March. There are lots more details, check it out at **http://SBAGreaterNE.org/** (there's a link at the bottom of the page) or call Ellen, or call Spaulding directly at 877-576-7272.

Spring is coming so either hang in there or hurry up and do something!

Jean Driscoll

This is her, winning the Boston Marathon. Not sure what year this was, because she did it <u>eight</u> times. That's amazing. I mean really amazing. Not amazing like the throwaway overused version of the word that we all use when something is good, but actually not even close to amazing, but literally amazing. As in 'I am amazed because I didn't think a person could do that'. Maybe we're not as amazed as we should be given that a certain ersatz cycling legend won a certain world-renowned cycling's version of the Boston Marathon seven times, but now we know why. What a great opportunity to renew our amazement for legitimate competitive excellence! How did an ordinary small-town Midwestern girl born with Spina Bifida grow up to do such amazing things? I don't know, at least partly because she had big dreams and big determination. Why am I talking about her right now? Well, that I do know.

Later this year, around mid-June, one deserving constituent* will receive the SBAGNE Jean Driscoll *Dream Big* Award. Not insignificantly, this award provides not only honor but also a check for (think Austin Power' Dr. Evil as you read this) one THOUSAND dollars. What does it take to win this award? You've got to have <u>dreams</u> and <u>determination</u> to make those dreams reality, and you've got to have <u>plans</u>, and you've got to <u>apply</u>. 'Plans' means a plan to spend the money doing something related to your dreams, a program, a school, or something similar. So giant, well laid out plans aren't necessary though that would be impressive. Apply by filling out our short little form, you can download it from **http://SBAGreaterNE.org/programs-services/financial-programs/jean-driscoll-award/** or you can call the very friendly Ellen at (888) 479-1900 and she will mail you one. You can apply for yourself of course, but you can also apply in the name of a qualifying constituent whom you know well. The deadline for receiving applications is May 16, but you know how these things go. If you don't start it now, you'll barely get it in on time if at all. We'd love to hear from you.

*A person living with Spina Bifida in Massachusetts, Maine, New Hampshire, or Vermont. You also have to be 14 or older.

Thanks for reading, and I hope you enjoy the rest of our newsletter!

Waltham, Massachusetts Holiday Party 2012

On Sunday December 2nd approximately 100 SBAGNE families and individuals living with Spina Bifida found the Hyatt House, Waltham (last minute change!) for the Annual Holiday Party. The children had the opportunity to play games, make penguin hats and reconnect with friends. Santa arrived with gifts for all the children and did a room quieting reading of the Night Before Christmas. Much appreciation to Santa for joining SBAGNE. Recognition to Dan, Big Top Music, who provided fantastic background and dancing music throughout the afternoon. The dance floor was full to most of the afternoon. Thank you to Dan for stepping in for Olypsys at the last minute. Olypsys, lead singer Patti Panzarino - Ms. Wheelchair Massachusetts 2012, were scheduled to play, but alas Patti was ill and could not join us. The adults loved the Yankee Swap. After much trading, who finally went home with the car reindeer nose and antlers?

It was wonderful to see old friends and make some new friends as well. Finally thank you to our elves for insuring the day went smoothly – The Amaral Family, Amelia, Patricia, Erica and Leanne Cordischi, Arielle Chalif, Emily Dugan and Katie and Cara Packard. We could not do this without your energy and assistance!

SBAGNE is looking forward to the 2013 Holiday Party - where we hope for no last minutes changes of hotel or illnesses! Thank you all for joining SBAGNE to celebrate the holiday season.

WE COULDN'T DO IT WITHOUT YOU

Thank you to our *Massachusetts* Elves for their assistance on December 2nd!

The Amaral Family

Patricia, Erica and Leanne Cordischi

Arielle Chalif

Emily Dugan

Katie and Cara Packard

Amelia Cordischi - Photographer

Thank you to our *Maine* Elves for their assistance on December 15th

Meredith Podgurski

Ed Podgurski

Cindy Pooler

Stephanie Glatzer

Your energy, assistance and flexibility insure the SBAGNE Holiday Parties were enjoyed by all.

Check out all the
Holiday Party Photos at
www.SBAGreaterNE.org!

Augusta, Maine Holiday Party 2012

The Senator Inn, Augusta ME was the site of the 2nd Annual Maine Holiday Party on Saturday December 15th. 80 SBAGNE families and individuals living with Spina Bifida joined enjoyed lunch with a delicious blueberry cobbler for dessert. The children decorated holiday cookies and t-shirts while connecting with friends. Santa arrived with treat bags for all the children, and made note of their wish lists. Thank you to ukele group that provided wonderful holiday sing along music for the afternoon.

Taking Care: Lessons from Mothers with Disabilities

Mary Grimley Mason with Linda Long-Bellil

“This is the hardest thing you will ever do”, says Melanie, a young disabled mother with cerebral palsy, about raising a child, but she goes on to say that it is fulfilling, joyous and “an amazing gift”. Melanie’s voice echoes many mothers with disabilities, who share many issues about parenting with all mothers but who have additional social, environmental and physical barriers to overcome in caring for their children. Despite the special challenges disabled parents face, approximately 8 million adults with disabilities in the United States are parents. The higher percentage are disabled women.

Taking Care: Lessons from Mothers with Disabilities gathers together some of the lessons learned from the experiences of mothers with disabilities. The successes of these women as mothers challenge stereotypes about good mothering. The barriers they encounter show the need for better accommodations from the society in which they live. The book, based on twenty-six interviews and other autobiographical narratives, covers the mothering cycle from pregnancy and birth to raising a child through young adulthood. These women’s stories reveal major themes which have shaped their experience of motherhood and which can offer a significant model for all parents.

Taking Care: Lessons from Mothers with Disabilities by Mary Mason-Grimley is available at **Amazon.com** and **BarnesandNoble.com**. Linda Long-Bellil is a Board Member of SBAGNE.

Jean Driscoll Award Announcment

Jean Driscoll

The SBAGNE Board of Directors is now accepting applications for the Annual *Jean Driscoll Award*. The SBAGNE offers this **$1000 scholarship** as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult with Spina Bifida. The award may be used for educational, developmental or assistive programs and needs and will be awarded to an SBAGNE constituent, age 14 or older, with Spina Bifida who best demonstrates the character and determination of the scholarship’s namesake.

SBAGNE is ***accepting self-applicants or the nomination of an individual*** for this award.

Please go to **www.SBAGreaterNE.org** for the official posting and application.

BLING

Better Living N' Girls

BEST

BLIN’G AND BEST WEEKENDS

in collaboration with Children’s Hospital-Boston

BLIN’G and BEST weekends are for tweens and teens ages 12-17, living with Spina Bifida and a parent. The weekend consists of education, social and recreational activities. Two nights in an area hotel, meals and activities are included. Cost $25 per family.

BLIN’G (Better Living N’ Girls) Weekend
March 1-3rd, 2013

BEST (Boys, Esteem, Success and Training) Weekend
April 26-28th, 2013

If you are interested in participating contact Ellen at 888-479-1900 or at **edugan@SBAGreaterNE.org**.

Watch your mail and visit **www.SBAGreaterNE.org** for additional information.

by **Virginia Briggs, Ph.D.**

Keeping the Bladder Healthy (A Review of Surgical Options for the Neurogenic Bladder)

Most people with Spina Bifida and their parents know that clean intermittent catheritization is one of the best ways to stay dry and keep the bladder (and kidneys) healthy. Generally, about two-thirds of people with Spina Bifida can become socially dry with catheterization, but one-third require surgery. Here is a summary of the surgical options available to people with neurogenic (dysfunctional) bladder.

- **Botulinum Toxin (Botox)** – Botox injection into the bladder which temporarily increases bladder capacity and decreases pressure. The injection is done under anesthesia as outpatient surgery, and is generally well tolerated. The results last several months.

- **Transurethral Electrical Bladder Stimulation** – The bladder is stimulated with electrical currents. The treatment is generally administered in twenty, 90-minute sessions. The results are varied, but have shown to be effective in up to 60% of patients.

- **Sacral Neuromodulation** – This is an implantable device that is thought to improve bladder function by either stimulating the nerve roots or by providing rhythmic contractions of the pelvic floor. The device consists of a pacemaker placed in the buttocks area, and a lead tunneled under the skin to the sacrum (S3). Improvements in bladder and bowel control have been reported in some studies, but additional research is needed to know how well this works.

- **Xiao Procedure** – This has been reported in previous issues of the SBAGNE newsletter and discussed at length at the Spina Bifida Research Congress in both 2009 and 2012, as well as the SBA National Conference. The procedure involves re-routing the nerve that controls bladder function to a different place on the spine. By using a nerve higher in the spine to control their bladder (usually lumbar 5 or above), the person can cause their bladder to empty by simply scratching their leg in a certain place. The results of research are encouraging, but researchers and physicians still feel that patients should be followed longer to know how well this really works. To date, only two centers in the United States are offering this procedure, one in Detroit and one in Tampa.

- **Reconstructive Bladder and Bowel Surgery** – Bladder reconstruction involves the enlargement of the bladder with a piece of intestine to increase bladder capacity, which lowers pressure. Bowel reconstruction refers to the "ACE" (antegrade continent enema) procedure, where an opening is placed on the belly. This allows the person to administer their own enema by inserting the solution directly into this opening which flushes the colon. A valve is created so stool will not leak out of the opening. This surgery can be performed as outpatient, or with a short stay in the hospital.

- **Bladder Neck Procedure** – This procedure aims to tighten the outlet of the bladder, to reduce leakage of urine. It is best to stop leaks when there is low pressure in the bladder (the bladder is not that full), but doesn't work well to prevent high pressure leaks (when the bladder is full). This is usually done the same time as bladder augmentation, but some urologists have suggested that performing the bladder neck procedure alone may work in some patients.

- **Tissue Engineering** – Research is underway to manufacture tissues in the laboratory that can be used to augment or reconstruct bladders, rather than using a piece of the intestine. This has been successful in animals, but not in humans yet.

People with Spina Bifida considering one of these options should discuss their questions and concerns with their physicians. Some procedures may work better than others for different people, depending on general health, lifestyle and longterm goals. Urological care is a two stage process, first to medically manage the condition (and protect the bladder and kidneys) and second, to stay dry and gain independence. A supportive family, and a good team of specialists is essential to helping a person with Spina Bifida navigate that long road, make the right decisions, and to live a healthy, happy, and independent life!

WALK-N-ROLL®
for Spina Bifida

Make plans now to join the Spina Bifida Association of Greater New England at its 4th Annual **Walk-N-Roll for Spina Bifida®** on **Saturday, June 15 at Massachusetts Hospital School in Canton, MA, Stanley Park in Westfield, MA and Rock Church, Scarborough, ME**. You pick the location that works best for you!

The Walk-N-Roll for Spina Bifida is a family-friendly, walk event being held to raise awareness about Spina Bifida and celebrate the accomplishments of the over 166,000 Americans living with it . All proceeds are used for programs and services for people living with Spina Bifida. Visit **www.walknrollsbagreaterne.org** for more information!

Interested in participating as a walker, team captain or planning committee volunteer? Contact **Wendy Potts** at **wpotts@SBAGreaterNE.org**.

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Join the
Spina Bifida Association of Greater New England

Late Winter Swim and Sports

Saturday March 16, 2013
Mass Hospital School, Canton MA

10 AM to 3 PM

10-12 Swim in the fully accessible pool

12-1 Lunch (provided)

1-3 Activities in the gym (basketball, etc.) and bowling

Join us for all of the day or any part.

RSVP to Wendy at wpotts@SBAGreaterNE.org or 888-479-1900

Let us know how many in your group, ages
and if you will be joining us for lunch.

Disablility Issue or Human Being Issue?

***by* Kathie Snow, www.disabilityisnatural.com**

How many times have we thought, heard, or said things like:

1. He's very manipulative—we know children with disabilities learn to be manipulative at an early age.
2. She'll never be able to drive—she has Down syndrome (or cerebral palsy or whatever).
3. What do you expect—he has autism (or fetal alcohol syndrome or seizures or whatever).

Now think about other things you've thought, heard, or said—better yet, make a list!

How many times do we make assumptions about children or adults with disabilities that are based primarily on the person's diagnosis? How many decisions—*life-altering decisions for the person with the disability*—have been made based on these assumptions? How do we *know* the issue is a consequence of the person's disability?

Let's look at example #1. Amazingly, I heard this from different professionals, years apart. (Where *did* this mythical and goofy assumption come from?)

Physical and occupational therapists at the center where I took my young son, Benjamin, shared the manipulation story after I complained that babies and toddlers with disabilities were crying during therapy sessions. As a mother, it seemed obvious the children were in distress—scared, tired, hungry, wet, had gas, or whatever—and were communicating their distress just like children without disabilities! "Nope," the therapists said, "kids with disabilities—*even six-month-olds*—cry just to get out of doing therapy; it's pure manipulation." (FYI: Few of the therapists had children, so they had no experience as mothers.)

The kindergarten teacher shared a similar view when five-year-old Benjamin sat motionless, "doing nothing," during some classroom activities: he was "non-compliant and manipulative." The reality was that she gave him the same paper and crayons as the other kids, instead of the materials I had sent from home. *He* knew he could not color without his easel (with the paper taped to it) and his huge markers. He did nothing because there was nothing he *could* do.

Looking at #2, how do we *know* a person cannot drive just because she has Down syndrome (or any other diagnosis)? How would we know unless she has an opportunity to try? She might need lots of practice, adaptive driving aids, etc. And maybe even then she won't be able to drive for whatever reasons, but it's patently unfair to use a diagnosis, in and of itself, as the rationale to deny her the opportunity. Consider: aren't there people who *do not* have disabilities who are lousy drivers and shouldn't be on the road—like the one next to you at the traffic light?

Now on to #3. In so many instances, a person's behavior is seen as a consequence of the disability, as in, "People with autism 'go ballistic' *because* they have autism." You can substitute any other diagnosis or behavior.

More examples abound—I've heard tons from parents, teachers, staffers in adult services, and others. A child in a general ed classroom hides under his desk because he has Down syndrome. But maybe he hides because he's afraid, not because he has Down syndrome. Another child pulls a classmate's hair or spits because she has [whatever disability]. But maybe it's because the classmate teased her and she's defending herself. An adult throws his food at dinner in the EBD (emotional-behavioral disorder) residential facility—whaddya' expect—he has an EBD. But maybe he hates the food on his plate, or he's got an upset stomach, and he has no effective means of oral communication, so throwing food is the only way he knows to express his emotions—*and* throwing food and other "inappropriate behaviors" are actually the norm in the EBD environment—the "inmates" learn from each other. Ironically, people who *do not* have disabilities who behave in the most outlandish ways often end up on the evening news or get their own reality TV shows! Go figure...

Many people erroneously perceive that every trait, characteristic, or behavior is a consequence of a person's disability (and this perception is just that; it's not a fact or the truth), and this can lead to a host of negative outcomes, including, but not limited to:

- We think we must address the "problem" by writing a goal to remedy it;
- The person with a disability may be punished;
- We don't look beyond the person's actions to discover what the real issue is;
- The person with a disability may be prevented from doing what's important to him/her (like driving, getting a real job, being included in ordinary activities, etc.);
- "Placing" the person with a disability in more restrictive, sheltered, segregated environments.

Many of the situations we deal with are *not* disability issues, they're *human being issues.* So it's time to respectfully, thoughtfully,

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Disability Issue, continued from pg. 7

and creatively separate the two in our homes, classrooms, and workplaces; in churches, synagogues, mosques, and other community activities; in treatment settings; and during team meetings.

Any child who's frightened may cry or hide under a desk; *any child* who's been teased may retaliate by pulling hair or spitting. A person who doesn't have effective oral communication will communicate through his behavior (so he needs a communication device). And many who *do* have effective oral communication *also* communicate through behavior: ever crossed your arms in disgust while giving a fake smile and nod of agreement? Does a person's "inappropriate behavior" really represent non-compliance or is he protecting himself or expressing self-direction (aren't these valuable, normal, and healthy attributes)? Maybe he's tired of being pushed around (literally) in a manual wheelchair and needs a power chair so he can be free!

Is a teen's behavior a consequence of the disability or does it reflect ordinary, hormonal, teenage angst? Is an angry outburst related to the disability or is the person stressed because his grandmother recently died? Does a person *still* need the job coach because of his cognitive disability, or is he not learning the tasks because he hates the job? Is the person having a meltdown because of the disability or is she just having a bad day (don't we all have bad days)? When a child responds negatively to the aide in the classroom, is it because of the disability or is he reacting to the insult to his dignity (he's embarrassed at being attached-at-the-hip to a grown-up)?

When you're in the middle of a situation, it can be hard to see the forest for the trees, so start by talking to the person with a disability (and presume competence when doing so). It's also beneficial to ask others for their views; lots of opinions *and* differing opinions can help us determine what's really going on.

Separating disability issues from human being issues can generate positive change for people with disabilities (and result in more appropriate solutions if solutions are necessary), and can also be incredibly freeing to parents, teachers, staff, etc.: "He's being a five-year-old [or having a bad day or whatever]; no worries—this, too, shall pass."

People with disabilities are more *like* people without disabilities than different: they feel, they grow, they succeed, they fail; they're human and they have normal human experiences. Let's not mislabel those experiences, and make things worse with inappropriate reactions, nor minimize *or* enlarge the experiences. Instead, let's recognize and celebrate them for what they are: ordinary *and* valuable similarities that bind us all together as members of the human race.

Finding the Right Vehicle and Adaptive Equipment

by Eric Lajeunesse, www.ride-away.com

Purchasing a vehicle is not a simple chore. With many vehicles to choose from, individuals and families must spend a great deal of consideration and time determining what works best for their situation and which vehicle featues are important to them. For those with disabilities and their caretakers, the decision to buy a vehicle is much more complicated. Fortunately, modified vehicles are becoming more and more available to the general population. Although these vehicles are readily available, the process of purchasing the best option for your situation comes with challenges. Individuals and families need to be able to make informed decisions before making the purchase to avoid spending a lot of money on a vehicle that does not serve their needs.

It is important to work with a qualified mobility dealer that can provide a tailored solution for your mobility needs while helping you through the purchase process. Start by chosing one that is certified by an organization known as the National Mobility Equipment Dealers Association (NMEDA). This organization offers certification through its Quality Assurance Program (QAP). The Quality Assurance Program is the only program of its kind that has been developed for the mobility equipment industry. A QAP designation endures you that the mobility dealer meets high standards of service, the installation of modifications and adaptive equipment are consistent and the dealer is committed to the industry's best safety practices. In order for a mobility dealer to gain the QAP Certfication, they must be inspected twice a year by an outside automotive engineering firm in order to assure that the dealer meets all these rigorous standards.

It is highly recommended to physically visit a qualitied mobility dealer and work with a Certified Mobility consulatant rather than purchasing a vehicle on the Internet. These consultants have a knowledge base similar to physical or occupational therapists. This allows them to be able to ask the right questions, take important measurements and evaluate specific needs for the individual with the disability and their family. They will demonstrate various adaptive equipment such as wheelchair lifts, hand controls and turning automotive seats. Additionally, they will show various modified vehicles with lowered floor conversions, lifts, raised roofs and raised doors.

The Certified Mobility Consultant will recommend the best mobility options essential to getting you on the road to independence. They are there to guide you through the vehicle selection process and the details of obtaining funding. They can provide information and work with available resources to help scquire funding for adaptive equipment and modified vehicles. In short, be sure to work with a QAP-certified NMEDA mobility dealer and make sure you work with a qualified local Certified Mobility Consultant who earn their living by helping people make the right mobility choice.

Visit the NMEDA website today (**www.nmeda.com**) and **www.ride-away.com** for more information.

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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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