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MESSAGE FROM THE CHAPTER CHAIR

The Chapter had its first annual Walk-N-Roll for Spina Bifida recently. This event is held by many local Spina Bifida Association chapters and is encouraged by our national organization. It is intended primarily as a public awareness opportunity, with a significant fundraising component. As this was our first time at this particular undertaking, there was a lot of planning and coordination necessary. Our event committee, chaired by college student Heather Horwedel, did an outstanding job: the event went off with minimal issues (especially if you thought to bring a jacket!).

I attended several of the committee’s meetings. I was pleased to see a number of “new faces” there as well as some familiar faces in new and challenging roles. I remember thinking, “THIS is what the Chapter needs in order to thrive.”

The Chapter is always looking for new ideas, new opinions, and especially for those people that can help make those ideas work. Several events – including our now-traditional snow tubing at Willard Mountain and the Walk-N-Roll – started off with someone’s idea or expression of interest; a committee was formed and the activity was on! If you enjoy any Chapter function or undertaking, please think about helping out! If you think that any Chapter function or undertaking could be improved, please think about helping out! If you have an idea for something new that we could do or if you would just like to assist with a new or on-going activity, please let us know!

It doesn’t take a lot of time. It doesn’t need to be a long-term commitment. However, only through the efforts of volunteers like the Walk-N-Roll committee will SBANENY be able to support the community in the manner we would all like.

**Kevin Chamberlain
Chapter Chair**

SBANENY Board of Directors

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Amy Clinton
Hali Holmes
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SBANENY CHAPTER PROGRAMS & ACTIVITIES

ADULTS!

EMPLOYMENT SKILLS FOR ADULTS WITH SPINA BIFIDA

GUEST SPEAKERS:

CRYSTAL COLLINS,

NORTHEAST CAREER PLANNING

CHRISTOPHER WALSH,

INDEPENDENT LIVING CENTER OF THE
HUDSON VALLEY

PANEL DISCUSSION –

SHARE YOUR TIPS FOR SUCCESS!

DATE: May 21, 2011

Time: 1 to 4 PM

Place: Independent Living Center of the
Hudson Valley, 13–17 Third Street, Troy, NY

RSVP: by Monday, May 16th

Activity:

- Employment presentation, discussions, and demonstrations
- Refreshments provided
- Tour of Independent Living Center of the Hudson Valley
- Independent Living Center of the Hudson Valley is on a CDTA Star Transportation route. If you need assistance planning transportation to the program, please contact our office today!

Parking: Free and plentiful on weekends.

Questions? Contact our office at 399-9151 or sbaneny@aol.com.

PARENTS!

BUILDING INDEPENDENCE: HOW TO DEVELOP BETTER ATTENTION & INITIATION, PART 2

Our Young Families program hosted a viewing of the SB University presentation "Building Independence: How to Develop Better Attention & Initiation." While the children were busy doing craft projects, playing games, and trying our Krazy Karr with Heather & Christina, the parents in attendance had an opportunity to watch the video, stopping for discussion and sharing of ideas and resources. We all left with a better understanding of the impact that challenges with Executive Functioning have on many children with Spina Bifida. We agreed that future presentations and discussions related to this topic would be beneficial to the children and caregivers.

We completed watching the first half of the video presentation available. We are planning an opportunity for parents to view the second half of the presentation together. Attendance at the first program is not required to attend Part II.

Date: Saturday, June 11, 2011

Time: Noon to 3 PM

Place: SBANENY office, Scotia

Childcare: Available for parents attending the presentation

Pizza Lunch: Served at Noon

Advance Registration Required.

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HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP

SPONSORED BY
SPINA BIFIDA ASSOCIATION OF
NORTHEASTERN NEW YORK



SCHOLARSHIP RECIPIENTS ANNOUNCED

We are pleased to announce that three of our young people have been awarded scholarships through the Helen R. Mertens Scholarship Fund. Congratulations to Alexa Wyszomirski, Grady Picinich, and Troy Thomas! The three recipients are all pursuing college degrees. They have each been awarded \$500 to support their educational goals. We wish them all well in their studies and continued success!

The scholarship fund was made possible through a bequest of the Helen R. Mertens Estate, with a generous contribution in 2011 from a member of our Board of Directors.

SPINA BIFIDA FAMILY RETREAT WEEKEND AT DOUBLE H RANCH

Date: October 21 – 23, 2011

Time: 6 PM Friday to Noon Sunday

Place: Double H Ranch, Lake Luzerne, NY

Who: Child with SB (must be aged 5 to 21) and their immediate family.

All participants must submit the necessary Double H applications by October 7, 2011. Registration forms are available to download at www.sbaalbany.org. If you don't have access to the internet, please call our office and we would be happy to mail registration forms to you.



SBANENY IS ON FACEBOOK!



Visit our page, post SBANENY and Spina Bifida related messages, pictures & suggestions.

EMPOWERMENT THROUGH INFORMATION:

LIVING WITH SPINA BIFIDA FOLLOW UP SURVEYS

Thank you to everyone who completed our conference follow-up survey. We are grateful to chapter volunteer Danielle Garfinkel who has completed a professional analysis of the data. We will be sharing these results with the foundations that helped to fund the 2010 conference. In addition, our conference committee will utilize the results to plan the next SBANENY sponsored conference on April 28th, 2012 and to apply for funding to support the event.

SPEAKING OF...

LOOKING TO GET INVOLVED?

CONFERENCE COMMITTEE 2012 WELCOMES NEW MEMBERS!

The SBANENY Conference Committee which will be coordinating our second local conference will begin holding planning meetings soon. Meetings are held at our office (Socha Plaza, 123 Saratoga Road, Scotia). They are generally once a month and we are looking for people to assist in all areas (such as procuring speakers, soliciting food and donations...), spending as little or as much time as they choose. The conference will be held on Saturday, April 28, 2012 and after last year's success, we're excited about making this year's conference bigger and better!

Should you have any questions or if you'd like to volunteer, please call Vanessa Chamberlain at 393-4834 or you can call our office at 399-9151.

REGISTRATION OPENS FOR 2011 SBA NATIONAL CONFERENCE

Today's Magic, Tomorrow's Vision

Registration for the 38th National SBA Conference is now open. *Join members of the Spina Bifida Community from June 26th to 29th at the Disneyland Hotel in Anaheim, California.* Hear national experts speak about issues related to Spina Bifida including;

- cutting edge medical therapies and procedures,
- managing stress,
- personal finance, and
- adaptive sports.

The schedule also provides many social and networking opportunities to meet other members of the Spina Bifida Community.

What can your children do while you attend programs? They will have a blast at SBA's Kids Camp! There is something for everyone.

Dates: June 26 – 29, 2012

Registration: Visit

www.spinabifidaconference.org for information and online registration.

Reservations: Reservations can be made by calling the resort directly at 714-520-5005 or emailing dlr.convention.groups@disney.com.

Book your hotel room as soon as possible to take advantage of discounts being offered to Conference attendees. Be sure to tell them that you are with the Spina Bifida Association's national conference.



SPINA BIFIDA UNIVERSITY OFFERS EXPANDED OPPORTUNITIES FOR LEARNING

There are dozens of sessions available through SB University. More recent topics that have been added include:

- Medical Management of the Neurogenic Bladder (Birth to Age 10) by Elizabeth B. Yerkes, MD, FAAP
- Sexual Function and Health in Men with Spina Bifida by John S. Wiener, MD
- Acido Folico Todos Mujer los Dias by Alina Flores, MPH

All sessions are available through www.sbuniversity.org.

NICHCY INFORMATION ON SUMMER CAMPS FOR CHILDREN WITH SPECIAL NEEDS (MARCH 2011)

The National Dissemination Center for Children with Disabilities (NICHCY) has updated its listing of information on camps and summer opportunities. Some of the listings identify camps available to all children, and some especially for children who have disabilities. (Many communities have additional summer camps or recreational opportunities available. For information on local camps/recreation, useful sources of information include parks and recreation departments, schools and teachers, religious organizations, other community groups, parent centers, and fellow parents.) <http://nichcy.org/publications/camps>

NICHCY "NEW TO DISABILITY" PAGE

The National Dissemination Center for Children with Disabilities (NICHCY) "New to Disability" page has information and resources for families and educators just entering the world of disability. <http://nichcy.org/families-community/new-to-disability>

NICHCY information was excerpted from the National Center on Secondary Education and Transition E-News, which can be found at <http://www.ncset.org/enews/>.

OPTIMIZING YOUR HEALTH IN ADULTHOOD

BY THOMAS WEBB, MD, MSc

I'm getting older and need to find adult providers. How should I go about picking new doctors who are familiar with Spina Bifida?

There is very little research or reports on the care of adults with Spina Bifida, although the Spina Bifida Community is working to address this deficit. There are also not many clinics for adults with Spina Bifida. So how can we help ourselves and others? The first step is to identify your optimal adult care team based on your needs. You will need a good primary care doctor (family doctor) who is adept at co-managing and co-coordinating complex conditions. You may need to educate your primary care doctor about where he or she can go to get more information about Spina Bifida.

You will also need access to specialists in other areas such as neurosurgery, physical medicine and rehabilitation, urology, gastroenterology (or general surgery), orthopedics, podiatry (foot doctor), physical therapy/occupational therapy, and gynecology, as well as a braces specialist (orthotist), wheelchair provider, and counselor.

To find these health care providers, ask your pediatrician or specialist. Talk to others with a similar disability and health care needs. You could also talk with your MRDD service facilitator, case manager, advocacy organization, or disability agency. Consider a physician who sees both adults and kids since he or she is likely experienced in helping patients with transition issues.

What do I do to prepare for my first visits with these new doctors?

Before you choose your health care providers, find out if the office is physically accessible (parking, exam tables, restrooms, etc.), make sure the office is latex-free if this is an issue for you, and find out if the provider takes your

insurance. Then visit the new providers to determine if they are a good match.

You will need to ask your pediatrician and/or specialist to transfer your medical records to your new providers. Keep your own record of your medical history. If your parents have already started it, add to it and make it a habit to take these records with you to your appointments. If you don't have any documented records from your parents, start collecting history now. Begin a notebook that includes a summary of: surgeries (ask for reports); radiology procedures (ask for reports); illnesses needing ER or hospitalizations; medications and any reactions; equipment (dates of purchase/repairs and providers); and immunizations. An excellent resource for maintaining a health care summary is the Spina Bifida Association's *Health Guide for Adults Living with Spina Bifida*. Some Web sites also have health history notebooks to download.

It is important to know your medications, dosages, frequency, and reason for each. I recommend you keep this information on a card and carry it in your wallet.

Before the visit, write down your questions and concerns so that you remember them. Ask the provider any questions that will help you evaluate whether he or she is the right doctor for you. If you are worried about something, say so. If you don't understand, say so or ask, "Could you please repeat that?" Bring a friend or family member with you to help ask questions or make you feel more comfortable.

What screenings should I be getting now that I am older?

SBA's *Health Guide for Adults Living with Spina Bifida* has a complete list of guidelines for screenings and evaluations. In terms of medical screenings, adults age 18 and older should get blood pressure, height (arm span), and weight checked every year. Regular cholesterol testing should be done for men age 35 years and older and for women age 45 and older (or beginning at age 21 if there is a family history of high cholesterol or heart disease). Diabetes screening using a fasting blood sugar measurement should

be performed by age 45 or sooner if overweight. Repeat the screening every three years. Screening for colon cancer should begin after age 50.

For women, a gynecologic exam and Pap smears are recommended at least by age 21 (earlier if sexually active). Breast self exams should be done once a month – one week after each menstrual period – and mammograms should be done by age 40 (earlier if there is a family history of breast cancer).

Men should learn how to do a testicular self exam and this should be done once a month. Prostate testing typically begins around age 45 to 50.

What changes can I expect due to typical aging versus those resulting from my Spina Bifida?

Changes can occur in all the body systems. Some are directly due to Spina Bifida, some are caused by lifestyle choices, and some are due to aging. Some of the unique health care issues adults with Spina Bifida experience as they age may include:

- ~Uneven pressure on joints (overuse pain and/or arthritis and pain)
- ~Diminished muscle strength and endurance (decreased ambulation, mobility, transfers)
- ~Diminished nerve function (decreased sensation and decline in circulation in legs and feet)
- ~Changes in weight
- ~Decreased skin tone (increased risk of decubitus ulcers, abrasions)
- ~Loss of bone density from lack of bone stimulation from walking (risks of recurrent fractures)
- ~Obesity (from decreased mobility; obesity also can cause decreased mobility)

Keep in mind that there is plenty you can do to help prevent or reduce the impact of these issues. For instance, orthopedic problems can be minimized by using braces, canes, crutches, and walkers to maintain as straight a posture as possible and by using a properly fitted wheelchair and a chair with propulsion

assistance. Skin problems can be minimized by checking skin daily, wearing proper fitting equipment, wearing shoes and braces, using chair pads, doing wheelchair pushups, adhering to good nutrition, seeing a podiatrist regularly, and wearing pressure stockings if you have edema of the feet. Also check these spots every day with your mirror; elbows, hips, buttocks, behind the knees, feet, ankles, and heels.

Dr. Webb is a physician at Huntersville Pediatrics and Internal Medicine, Presbyterian Novant Medical Group, in Huntersville, N.C., and a Volunteer Associate Professor of Clinical Medicine at the University of Cincinnati College of Medicine.

*This article was reprinted from **Insights Into Spina Bifida®**, the Spina Bifida Association's national magazine. To order a subscription to **Insights**, please visit www.spinabifidaassociation.org.*

Dr. Webb's complete presentation of *Optimizing Your Health in Adulthood* that was presented at SBA's 2010 National Conference contains much more information about a variety of health care issues as they relate to aging and Spina Bifida. Review the entire presentation at www.spinabifidaassociation.org. (Visit the Events page, national conference, 2010 Conference Information.)

SBANENY DEVELOPMENT UPDATE SBANENY 2011 MARATHON UPDATE

WE NEED YOU!!!

**Please run for us in the Hudson-Mohawk
Marathon/Half Marathon October 9, 2011.**

**Wouldn't you like to run for
"Team SBANENY"?!**

**Your choice –
You can run a half or a full marathon!**

Right now we have a team of four runners and we are looking for more.

Read on for more details.....



Here is how it works and what each runner needs to do –

- Be willing to run a marathon or half marathon
- Train, run, train and then run some more!
- Have fun!
- Commit to raising \$1,500 or more in funds for our great organization!

What the runner will receive –

- Entry fee will be paid by SBANENY
- Running uniform and a training shirt will be provided
- Fundraising assistance with emails, website and other methods that will make it easy for the runner to raise the funds
- A way to get in shape for the summer (and fall!)
- A rewarding experience
- An easy way to get involved with SBANENY!

I ran this half marathon in 2009 and it was one of my favorite events I've entered in my running career. I remember it was a beautiful fall day that started with a slight chill in the air but by the time I was done it was 70 degrees and warm. The last 5 miles you run along the Hudson and that time of the year when the leaves are changing is really something to see. I also remember the beer at the end but that's another story and if you sign up to be on the team, I'll tell you that one!!

Any questions or to sign up, please contact Jim Gallagher through our office at 518-399-9151 or email sbaneny@aol.com.

All runners need to be signed up by June 15th.

Thanks,
Jim Gallagher

SBANENY INAUGURAL WALK-N-ROLL FOR SPINA BIFIDA Saturday, April 30th was a great day!

Not only did the weather cooperate, but the Inaugural Walk-N-Roll for Spina Bifida sponsored by Spina Bifida Association of Northeastern New York was a wonderful success! 100 participants joined together to celebrate the accomplishments of the people in our community living with Spina Bifida and to bring awareness to the public about the disability. In addition, the event was successful in raising funds to support the wide range of programs and services offered by SBANENY for individuals and families affected by Spina Bifida.

Thank you to everyone who made donations and to our walkers and team leaders! Prizes were award to participants;

Best Team T-shirts – Jayson's Troop
Team raising the most money – Team Nicholas
Team with the widest age range of participants – Team Nicholas
Most creative team name – Team Bumblebee
Team with most members – Roll Out
Individual raising most money – Mary Langelier
Individual coming from greatest distance – Courtney Williams

Everyone involved, whether walking, rolling, and/or donating were supporting the SBANENY mission; *to promote the prevention of Spina Bifida and enhance the lives of all affected by the disability.*

It's not too late to become a donor. Just go to www.firstgiving.com/sbaneny. From there you can make a donation to recognize one of our walkers, or make a general online donation to SBANENY.

Your support of SBA of Northeastern New York is important to us and we appreciate all that you do. We look forward to the 2012 Walk-N-Roll for Spina Bifida and hope that you can join us!

SBANENY CHAPTER CALENDAR

MAY

May 14

Board of Director's Meeting

May 21

Employment Skills for Adults with Spina Bifida

JUNE

June 11

Young Family Program –Building Independence Skills, Part 2

June 26 – 29

Spina Bifida Association National Conference

AUGUST

August 28

SBANENY Family Picnic

SEPTEMBER

September 10

Board of Director's Meeting

OCTOBER

October 9

Hudson-Mohawk Marathon –
SBANENY Runners!

October 21 - 23

Spina Bifida Retreat Weekend

NOVEMBER - DECEMBER

Date TBA

SBANENY Annual Fundraiser

SBANENY
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