

Spina Bifida

NEWS To Use

Albany/Capital District Chapter
109 Spring Road, Scotia, NY 12302
(518) 399-9151
SBAAlbany102@AOL.com



Dear Members,

Occasionally it comes to my attention that it may not clear to some people who this chapter provides services to and what the meaning of a paid member is. I decided to address this letter for the newsletter to "members" to take the opportunity to clarify this.

Each year in beginning in February and ending in March we hold a membership drive. This is an opportunity for those who are able to submit a paid membership, \$20 of which goes to our national organization, Spina Bifida Association of America, and \$5 which stays with our chapter. We had a very positive response to this drive this year. It is with this support of numbers of paid members that we are able to stay registered as a chapter of the national organization.

This paid membership, however, is not a requirement for individuals and families to receive services from our chapter. *Basically, any individual who lives in our geographic area who has Spina Bifida (or a disability resulting in similar complications), or their family members, who calls, emails, or is referred to us requesting assistance is put on our list and will begin to receive mailings, information or support services.*

Along with this clarification, I need to correct information from the last newsletter regarding the Helen R. Merten's Scholarship. *Paid membership in our chapter is not a requirement to be eligible for the scholarship award.* You will find further information about the scholarship inside.

We are working on several chapter activities over the rest of this year. The next is a family outing to Mohunk Mountain House on Saturday, April 29th. If you have not already made a reservation in response to my email invitation, please complete the attached reservation form as soon as possible. We need to know who will be attending so that we can make appropriate plans for the day and therefore make it successful and enjoyable for all. We are especially hopeful that this event will be a convenient location for those members south of Albany. We hope to see you there! Thank you for your quick response!

Karen Wentworth
Administrative Director

Albany Patroons Basketball Game

From Jonathan & Katie

The Albany Patroons game was fantastic!!!! We loved every minute of it. Our seats were nice and close to the basket and there was a lot of action. It was a high scoring game which we loved. They kept dunking it and hanging from the rim. All the things that professionals do on TV. It was a great sporting event to go to because our seats were so close to the action.



Do you like music?

Would you be interested in participating in a choir or singing group?

In response to our recent membership questionnaire, we have a member who suggested this type of activity might be offered by our chapter. If this is something that might interest you as well, please call or email. We will work with those interested to explore how this interest might be met!



Reminder...

Helen R. Mertens' Educational Scholarship

Sponsored by the

Spina Bifida Association: Albany/Capital District Chapter

Purpose...to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. Please call, email, or visit our website at www.SBAAlbany.org for further information and to learn about how to apply.

CORRECTION from previous publications.

THERE IS NOT A PAID MEMBERSHIP REQUIREMENT FOR ELIGIBILITY FOR THIS SCHOLARSHIP. We apologize for any inconvenience that this may have caused.

Skating at Union College with Women's Ice Hockey Team

A group of our families had the pleasure of joining the Union women's ice hockey team on the ice during February vacation last month. While the skating was perhaps more relaxed for the team, it was a blast for our families who attended. We are grateful to the team for hosting our group and are glad that they were able to join us after for pizza and hot chocolate. This was a great perk for our kids to be able to get together with the Union College women's ice hockey team for a skate.

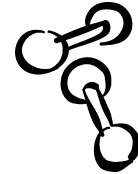
Union head coach Tim Gerrish and his team showed their excitement over having the opportunity to spend some time with kids, parents, and staff from our chapter.

And stay tuned for next year..... Coach Gerrish and the team have already invited us back next year. They plan to host our group at a women's ice hockey game followed by an open skate with them after the game. We will be watching for a Saturday game in January and hope to have many families able to attend!



National Center on Physical Activity and Disability (NCPAD) gives resources to promote substantial health benefits that can be gained from participating in regular physical activity based upon “Exercise is for EVERY body”, and every person can gain some health benefit from being more physically active. This site provides information and resources that can enable people with disabilities to become as physically active as they choose to be. There is a section with information specific to people who have Spina Bifida with topics including

- * Importance of Exercise
- * Important Considerations When Exercising
- * Important Safety Considerations
- * Cardiovascular Training Guidelines
- * Strength Training Guidelines
- * Flexibility Training Guidelines



Visit www.ncpad.org for more information.

Dolls With Physical Disabilities

Are you interested in finding a doll that uses a wheelchair, walker, or crutches? You might be interested in Beyond Play Dolls. Visit <http://www.beyondplay.com>.



Adaptive Yoga

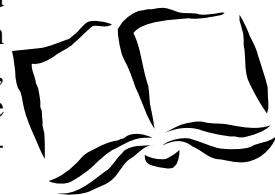
Center for Disability Services
314 S. Manning Blvd, Albany
Mondays 5:30—6:30 PM
Tuesdays Noon to 1:00 PM

To register... or for more information, contact Jean Murawski @ 437-5575 or Richard Vassi @437-5714

Programs are customized for those with disabilities.



Out of the Bottle is the story of Graham Webb, a high school dropout at age fifteen, who grew up in London, in government subsidized housing, and overcame the challenges of spina bifida to forge a name in the world of business and hair care. Graham Webb has been knighted by Her Majesty the Queen for “Services to Business, and Charity in Kent.” See <http://www.out-of-the-bottle.com>



2006 Spina Bifida Symposium May 10-12, 2006 Chicago, Illinois 773-880-4373

Visit www.childrensmemorial.org/cme
(click on live events)

David G. McLone, MD, PhD
Robin M. Bowman, MD
Symposium Co-Directors

Joy Ito, RN
Roseann Greene, RN
Symposium Coordinators

Children's Memorial Hospital
Chicago, Illinois

College Planning for Students with Disabilities

(Handbook)



This handbook from Project NETS at the University of Nebraska-Lincoln and the EducationQuest Foundation is for students with disabilities planning to attend postsecondary education institutions and their parents or guardians. Its sections include

- Know Your Disability
- Academic and Career Planning
- College Selection
- College Funding
- Requesting Services and Accommodations
- Legal Rights and Responsibilities

Available in PDF (19 pages, 1.7 MB).

<http://www.answers4families.org/family/pdf/DisabilityHB.pdf>

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

Research Articles Online

— Online Resource

Now Updated

SBA National Office has recently updated the results of a quarterly scientific publication search on Spina Bifida and related topics on the web in Research Articles Online. This new Resource Center section features highlights of research articles on topics that are most frequently requested by National Resource Center patrons. Go to:

<http://www.sbaa.org>



Cecostomy information at

[Http://cecostomy.4t.com](http://cecostomy.4t.com)

The cecostomy website offers information to give the visitor a better understanding of what a cecostomy is, the steps in cecostomy surgery, and how to maintain a cecostomy. Topics include how the digestive system works, how to give an antegrade enema and the importance of fiber and water. The website also offers specific information related to those with Spina Bifida.



Colburn National Foundation

270 West Circular Street
Saratoga Springs, NY 12866
518-226-0252

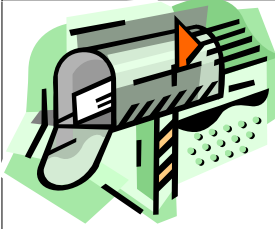
The Colburn National Foundation is a not-for-profit New York State public charity dedicated to children with disabilities and their families who reside within a 50-mile radius of Saratoga Springs, NY. The Foundation provides resources for financially-challenged families in order to promote independence and passionate participation for individuals 21 and younger.

Contact the Foundation directly for further information.

Y-Knot Offers Accessible Sailing for all on Lake George

Participation in a sport like sailing builds confidence and self-esteem, while it challenges the whole person. Y-Knot is all about sailing — regardless of your experience or physical abilities. If you're someone with a disability looking for a new challenge, or an able-bodied sailor interested in seeing your sport in a completely new light you might enjoy trying this out. The Yknot program seeks to “leave our disabilities on the shore.” For more information visit www.yknotsailing.org or call 518-656-9462.





Have you moved?

If you have moved and are still in the eastern part of New York State, your newsletter from our local chapter will be forwarded by the US postal Service for a period of time but will eventually be returned to us as not deliverable. If you would like to continue to receive the newsletter and have moved, please remember to update your address with our chapter.

Reminder to paid members:

The newsletter of our national organization, Insights, is sent to you by bulk mail, which the US Postal Service **will not forward**, and thus it is essential that we receive address updates for you to continue to get your subscription.

For those who have email...

There is sometimes information that we pass along... about upcoming events or opportunities... that can't wait for the next newsletter to come out. We send this out by email. If you have email and don't receive periodic notices from SBAAlbany102@aol.com you may need to update your information with us. Just send us an email and we will add or update your email address.

Planning Ahead?

In September Windham Mountain Adaptive Sports program is going to have clinics for the disabled to try **sled hockey**. If you think that you might be interested, pencil this in on your calendar for September 9 & 16, 2006. We will get further information to you as we learn more details. (See February 2006 of the newsletter for a description of sled hockey.)



Freihofer's Community Walk

Date: Saturday, June 3, 2006

Time: 8:15 AM

Place: Empire State Plaza,
Madison Ave, Albany

Who: Members, family, friends

Why: The community walk has given our chapter a fun activity to do together while raising money to help to support chapter activities. Please consider joining us!

Special Needs Estate Planner

Jones & Wilcenski, PLLC offer an e-newsletter for individuals with disabilities, their families, and their advocates. This newsletter covers a wide range of issues, including special needs estate planning, elder law, guardianship, special needs trust administration, government benefit law and advocacy. It is provided at no charge to clients, friends and colleagues of Jones & Wilcenski, PLLC.

The most recent article is "What Now?": The Importance of Educating Your Guardians and Trustees."

Previous topics include:

- Supplemental Needs Trusts for People with Disabilities
- Special Needs Estate Planning for Persons with Disabilities
- Transition Planning: Other Things to Think About
- The Importance of Advance Health Care Directives for Individuals with Disabilities
- Medicaid: Changes are on the Horizon
- Things to Consider Prior to Your Special Needs Estate Planning Consultation
- A Refresher on the Supplemental Security Income Program
- Should I Agree to be a Trustee?

If you would like a copy of any of these newsletters, please contact us and we will be happy to help you.

Jones & Wilcenski PLLC
5 Emma Lane
Clifton Park, NY 12065

Ed Wilcenski is the lawyer who presented to our group at Double "H" Hole in the Woods last fall.

All I Want For Christmas Is A Bike

by Victoria Onderdonk-Milne

One week before Christmas 2005 Marina Onderdonk-Milne became 1st recipient in NYS of a hand-powered bike from the Marine Corps League. These wonderful volunteer “elves” made Marina’s dreams come true.

It was Marina’s biggest wish for Christmas to get a bike to ride alongside her brother Christian, age 10, and her sister Lexi, age 15. Marina’s father Nicholas and I had tried all different things – both seats attached to our bikes and tandems, to help Marina in her desire for a bike ride. However at age 5½ she was starting to outgrow everything available in the stores. We were trying to explore all other options. It seemed that our only option would be a hand-powered bike. Since the bikes we saw were very expensive we turned to Karen Wentworth, Albany/Capital District Chapter of the Spina Bifida Association executive director, to see if she knew of any places to rent or purchase a used bike.

It was then the Christmas miracle occurred because just a few days before she had been contacted by Marine Corps League representative, Carol Baum, regarding a bike. We were put in touch with Mrs. Baum who did all the paperwork, took Marina’s measurements, and chaired the Marine Corps League Bike Gift.

On that December day our entire family arrived at a warehouse in Rotterdam filled with toys collected by the Marine Corps for Toys for Tots, “It is one of Santa’s store-rooms,” said the representative who greeted us, “we are the elves.” As these smiling faces presented a gift to each of our older children and led Marina to the bike, our hearts felt like they were angels. Marina excitedly rode the bike in the warehouse and when they told her Santa left it for her, she screamed in delight.

It was a Christmas gift none of us will ever forget. We look forward to many summers of Marina riding her bike and when she has outgrown it – passing it on to delight another child in need.

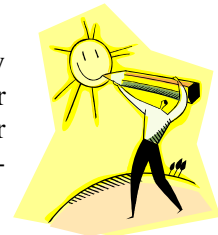
Thank you to all the wonderful people with big hearts who work for the Marine Corps League. We hope you are blessed as you bless the lives of others.

THANK YOU TO STEWART’S!

Many thanks to Stewart’s for a generous grant of \$750 through their Holiday Match program. Stewart’s program funds are designed to be used directly for children 18 years and under. This year’s grant will be helping to support our teen support group and accessible tennis lessons. We are grateful for the support that they have given to our chapter over the last 4 years!

THANK YOU TO WAL-MART!

We also recently received a grant from the Wal-Mart Foundation for \$1000. Wal-Mart is helping to pay for part of the expense for the chapter day outing at Mohunk. We are grateful for their support of one of our programs for families.



YOU ARE INVITED!

SBA: Albany/Capital District Chapter

is going to

Mohunk Mountain House Lake Mohunk New Paltz, NY

DATE: Saturday, April 29, 2006

TIME: 10 AM - 3 PM

WHO: Individuals (children or adults) who have Spina Bifida and their families.

ACTIVITIES: The recreation planners at Mohunk are working with us to plan activities.

***For planning purposes, it is important for us to know who will be attending.
Activities will be designed for that group .***

Thank you for your quick response so that the planning can be completed!

LUNCH: Will be included.

LOCATION: Mohunk is a spectacular resort located six miles west of the New York State Thruway near New Paltz. It is about 1 hour and 30 minutes south of Albany. We are sure that you will agree that it is well worth the trip! See directions below.

TRANSPORTATION: We are looking into helping to provide transportation for those who might have a need for this. Please call or email if having transportation would allow you to attend.

FEE: This activity is being sponsored by SBA: Albany/Capital District Chapter. We have received a grant from Wal-Mart that will cover the cost of part of the outing. There will not be a fee to individual participants, ***but we do need accurate reservations.***

QUESTIONS? Call 518-399-9151 or email SBAAlbany102@aol.com and we will get back to you.

RSVP: As soon as possible preferred. By Monday, April 17th.

Reservations will be on a 1st come 1st serve basis.

Coming from Albany & Northern Catskills

Go south on the NYS Thruway (I-87 south) to Exit 18, New Paltz.

After leaving the NYS Thruway at Exit 18, turn left at the traffic light onto State Route 299/Main Street. Follow Main Street through New Paltz.

Immediately after crossing the bridge over the Wallkill River, turn right (follow "MOHONK" sign).

After 1/4 mile bear left at the fork and follow Mountain Rest Road and Mohonk signs to the Gatehouse. (NOTE: The Mohonk Gatehouse is located about six miles west of the Thruway Exit.)

Coming from Southern New York

Follow main highways to Route I-84 (west). Follow Route I-84 to NYS Thruway (north). Go north on the NYS Thruway (I-87 north) one exit to Exit 18, New Paltz.

After leaving the NYS Thruway at Exit 18, turn left at the traffic light onto Route 299/Main Street. Follow Main Street through New Paltz.

Immediately after crossing the bridge over the Wallkill River, turn right (follow "MOHONK" sign).

After 1/4 mile bear left at the fork and follow Mountain Rest Road and Mohonk signs to the Gatehouse. (NOTE: The Mohonk Gatehouse is located about six miles west of the Thruway Exit.)

MOHUNK MOUNTAIN HOUSE RESERVATION FORM

NAME OF INDIVIDUAL WITH SB _____ **Age** _____

FAMILY MEMBERS	Relationship	Age (of children)
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_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Please indicate any special dietary needs: _____

Please mail reservation form to:

**SBA: Albany/Capital District
109 Spring Road
Scotia, NY 12302**

MOHUNK MOUNTAIN HOUSE RESERVATION FORM

NAME OF INDIVIDUAL WITH SB _____ **Age** _____

FAMILY MEMBERS	Relationship	Age (of children)
-----------------------	---------------------	--------------------------

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Please indicate any special dietary needs: _____

Please mail reservation form to:

**SBA: Albany/Capital District
109 Spring Road
Scotia, NY 12302**

**RESERVATIONS WILL BE ACCEPTED ON A
FIRST COME — FIRST SERVE BASIS.....**

RESERVATIONS DUE BY APRIL 17TH.....

**DAY EVENT AT MOHUNK MOUNTAIN HOUSE,
NEW PATZ.....**

SEE INSIDE FOR DETAILS.....

MAKE YOUR RESERVATIONS NOW.....

SPINA BIFIDA ASSOCIATION:
ALBANY/CAPITAL DISTRICT CHAPTER
109 SPRING ROAD
SCOTIA, NY 12302