

# Spina Bifida

December 2006

## NEWS

To Use

**Spina Bifida Association  
Albany/Capital District Chapter  
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www.SBAAlbany.org**



**EDUCATION \* SUPPORT \* AWARENESS**

Dear Families,

In my letter to you in the October newsletter, I talked about the mission of our organization: to promote the prevention of spina bifida and to enhance the lives of all affected. I enclosed with the newsletter brochures designed to educate people about spina bifida and invited you to request additional copies to distribute among family, friends, at work or church. Thank you to all who participated in this effort!

This month I am also enclosing information, this time related to folic acid. The week of January 7 – 14<sup>th</sup> is folic acid awareness week, designed to educate the public about the benefit of folic acid in your diet. Studies have found that taking folic acid before and during early pregnancy reduces the risk of spina bifida and other serious birth defects up to 70%.

Please read the enclosed brochure so that you can also help to spread this information to others. If you would be able to display posters with the folic acid message at work or church, or make brochures available in an office setting or local gym, please call or email and I will send your requested amount to you.

Our purpose as a chapter is twofold: to help to prevent spina bifida in future children, and to enhance the lives of those affected. Our board of directors is committed to doing both. We participate in the national campaign for prevention, and we also work to provide services, such as this newsletter, support contacts with individuals and families, and chapter activities, to enhance the lives of those affected and to raise awareness of spina bifida in our communities.

I wish you, your family and loved ones a healthy, happy, and peace-filled holiday season and New Year!

*Karen Wentworth*  
Executive Director



## Teen Support Group

The chapter's teen group meets each month at Colonie Community Center, 1653 Central Ave, Albany. The next meeting is scheduled for January 20, 2007. Is your teen interested in participating? Call or email for information and the schedule.

### Adapted Tennis Lessons

We are pleased to have Mr. Jim Neal, tennis coach and instructor, working with us to provide adapted tennis lessons for our teens and adults. Those participating are developing tennis skills and having a great time. Newcomers are welcome!



**Time:** Saturdays, 3 – 4:30 PM

*(Due to occasional conflicts, lessons might be cancelled, so please be sure to contact us if you plan to join the group so that we can put you on our contact list.)*

**Place:** Schenectady Racquet Club  
2699 Curry Road, Schenectady

**Cost:** There is no cost for participation

**Questions?** Are you interested in tennis but concerned how the lessons might work out for your particular needs or challenges? Please call and speak with us. Jim has experience adapting instruction and the game to adjust for various abilities.

**Would you like to join the lessons?**

Please call or email our office and we will be sure to get you the information.

### Directions:

1. TAKE EXIT 25 FROM THE NYS THRUWAY
2. TAKE 890 TO CURRY ROAD EXIT, 9A
3. BEAR RIGHT ON CURRY ROAD
4. LOOK FOR SCHENECTADY RACQUET & FITNESS SIGN ON RIGHT
5. TURN RIGHT ON ROAD JUST BEFORE THE SIGN

## Regional Conference Planned

The Connecticut chapter of SBA will be holding their 3rd Annual Educational Conference on Saturday, March 24, 2007. Mark your calendars and watch for details in future newsletters or emails.

## Families of Preschoolers!

You have asked for an opportunity to meet, talk, and share while your children get to play together & develop friendships. Please set this morning aside! We have a special education teacher who has volunteered to provide activities for the children while the parents meet with each other in the next room.

### Presentation: Special, Special Me

Self-esteem is a big concern for our children. How can we prepare them to be confident when they are asked questions or stared at because of their different-abilities?

**Guest Speaker:** Victoria Onderdonk-Milne is a certified NYS school counselor who has worked counseling & assisting children of all ages and their families. She is a clinically skilled chaplain working for Four Winds Hospital & Community Hospice assisting patients with grief, self-esteem and spiritual/emotional issues. Victoria is involved in wellness of mind, body & spirit and offers educational workshops, classes and support groups on a consultant basis. She and her family participate in many local activities and committees related to community advocacy efforts and organizations. Most importantly, she is a married mother of three children.

**Date:** Saturday, January 13, 2007

**Time:** 10—11:30 AM

**Place:** Colonie Community Center  
1653 Central Ave, Albany

**RSVP:** Please call or email...

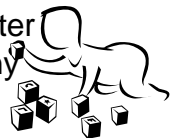
\_\_\_\_\_ # of adults

\_\_\_\_\_ # of children & their ages

\_\_\_\_\_ name & age of child with spina bifida.

**\* We need this information so that we can be prepared for the speaker and with appropriate childcare activities.**

**Childcare:** Provided by Special Education Teacher Chas Kelly



**Cheesecake Tasting  
Fundraiser**  
at  
**Cooperstown Bed & Breakfast**  
**88 Chestnut Street**  
**Cooperstown, NY**  
to benefit  
**Double "H" Hole in the Woods**  
Sunday  
February 11, 2007  
2—5 PM



**DIRECTIONS:**

- Take I-90/NYS THRUWAY toward I-88 (between Exits 25 & 26)
- Merge onto I-88 W via EXIT 25A toward SCHENECTADY / BINGHAMTON / RT-7
- Take EXIT 21 toward RT-7 / WARNERVILLE / RT-10 / COBLESKILL
- Turn RIGHT onto HITE RD
- Turn RIGHT onto NY-7 / NY-10
- Turn SLIGHT LEFT onto WARNERVILLE CUT-OFF RD / CR-23A
- Turn LEFT onto NY-10
- Turn LEFT onto NY-165
- Turn LEFT onto NY-166
- Turn RIGHT onto CR-52
- Turn LEFT onto BEAVER ST
- Turn SLIGHT RIGHT onto CHESTNUT ST / NY-28.

**Union College  
Women's Ice Hockey Game  
Be Their Guest!**

The families of our chapter have been invited to attend an ice hockey game as guests of the Women's Ice Hockey team. Mark your calendars! Please contact our office if you would like to attend so that we can give you the details of the event.

**Date:** Saturday, February 3, 2007

**Time:** Game time 4:00

**Place:** Frank L. Messa Rink at Achilles Center, Union College, Schenectady



**Directions:** Enter the campus from Union Street. Take the first left once on campus and the rink will be the second building on your left.

**RSVP:** Call 399-9151 or email

[SBAAAlbany102@aol.com](mailto:SBAAAlbany102@aol.com)

*Coach Gerrish is hoping that we might spend some time with the team on the ice after the game. He is working to schedule ice time for that day. If this doesn't work, he will be working to schedule some time for this activity during the February school break.*

# Mark Your Calendars!



- Folic Acid Awareness Week, January 7 – 14, 2007
- Preschool Families Group, Saturday, January 13, 2007
- Adapted Tennis Lessons, Saturdays, 3 – 4:30
- Teen Support Group, Saturday, January 20, 2007, 10 – 11:30
- Union College Women's Ice Hockey Game, Saturday, February 3, 2007
- Cheesecake Tasting Fundraiser for Double "H", Sunday, February 11, 2007
- Preschool Families Group, Saturday, March 3, 2007
- Connecticut Regional Conference, March 24, 2007

## What is Spina Bifida?

Often our children are asked this question. If you are looking for kid friendly ways to describe spina bifida, check out this website:

[http://kidshealth.org/kid/health\\_problems/one/spina\\_bifida.html](http://kidshealth.org/kid/health_problems/one/spina_bifida.html)



## Special Needs Estate Planning by

**Edward V. Wilcenski, Esq.**

The October 2006 newsletter for Special Needs Estate Planner addresses recent changes in guardianship law. Please let us know if you would like a copy and we will email or mail it to you.

## Bullying

Recently a news story came to our office about a teen with spina bifida who was the victim of bullying and was severely injured. From this, we are reminded how important it is to empower our children, especially those with special needs, to know how to respond if they are experiencing being bullied.

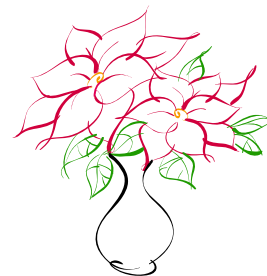


You might want to spend a few minutes looking at a website about bullying: what it is, how to respond to it, and how to prevent it. Check it out at [www.pacerkidsagainstbullying.org](http://www.pacerkidsagainstbullying.org)

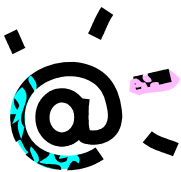
*Thank you to SBAWI, the Wisconsin chapter of our organization, for sharing this information for the benefit of all!*

## Latex Allergies --- Poinsettias!

As we celebrate the holidays, many families enjoy the foliage of a beautiful poinsettia in their home. Did you know that these can cause a reaction for someone who has latex allergies? The reaction is not exactly the same as with food because the latex protein in foods is just a bit different in plants. Plants can be a source of natural latex. Those with allergies can experience the same reaction to the plants that one might get with balloons, gloves, and other latex products.



## Newsletter by Email?



In our last newsletter, I invited anyone who might prefer to receive our newsletter by email to send me an email with the request. We had a number of families who chose this preference. Please contact our office if you would like to join the email list, saving paper and money for the chapter.

*Don't forget.... If your email address is changing, please let us know so that we are able to continue sending current information to you!*

## United Spinal Association

United Spinal Association is a 501(c)(3) nonprofit membership organization. Their mission is to provide expertise, create access to resources and strengthen hope thereby enabling people with spinal cord injuries and disorders (SC/D) to fulfill their potential as active members of their communities. Go to [www.unitedspinal.org](http://www.unitedspinal.org) for information. They accomplish their mission by:

- \* Ensuring quality health care
- \* Promoting research
- \* Advocating for civil rights and independence
- \* Educating the public and enlisting its help
- \* Expanding opportunities for all paralyzed Americans

## Spina Bifida Research Resource (SBRR)

The SBRR is a project, funded by the National Institutes of Health, to study the causes of spina bifida. The goal of the SBRR is to find genes and environmental factors that increase the chance that a child will be born with spina bifida or a related condition called anencephaly. To succeed, this project requires a partnership between scientists and families.

If you were born with spina bifida or you have had a child with spina bifida or anencephaly, you may join the SBRR. Families that join the SBRR are asked to complete an interview and to provide blood or saliva samples for genetic studies.

Participation in the SBRR does not cost anything and participants are not required to travel. The study interview is conducted by telephone and the study samples are sent by mail. The SBRR pays for all study related expenses.

If you would like additional information about the SBRR, please visit the SBRR website ([www.sbr.info](http://www.sbr.info)) or contact: Katy Hoess, M.S., CGC at 1-866-275-SBRR or by email at [khoess@mail.med.upenn.edu](mailto:khoess@mail.med.upenn.edu).



## Facts About the Americans with Disabilities Act

Title 1 of the Americans with Disabilities Act of 1990 makes it unlawful for an employer to discriminate against a qualified applicant or employee with a disability. For basic fact sheets about what is covered by ADA, go to [www.eeoc.gov/facts/fs-ada.html](http://www.eeoc.gov/facts/fs-ada.html) and [www.eeoc.gov/facts/jobapplicant.html](http://www.eeoc.gov/facts/jobapplicant.html). You will find information on topics such as:

- Medical Examinations and Inquiries
- Reasonable Accommodation for the Application Process
- Asking for Accommodation
- Discussing Disability with the Potential Employer
- Discussing Accommodation to Perform the Job
- Being “Qualified” for the Job
- Obtaining More Information about the ADA
- Filing a Charge of Discrimination



*If you are in need of this information and don't have access to the internet, call the chapter office and we will send you a copy in the mail.*

## Physical Activity for Individuals with Spina Bifida

The National Center on Physical Activity and Disability, in cooperation with the Spina Bifida Association of America, has published guidelines for physical activity for individuals who have spina bifida. You may wish to consider obtaining two resources available through this joint effort.

- Visit <http://ncpad.org> and view a preview of “Teens on the Move: An Exercise Video for Teens with Spina Bifida.”
- Visit <http://ncpad.org>, click on physical activity, then exercise/fitness, then exercises for individuals with spina bifida.



