

Spina Bifida

May 2007

NEWS

To Use

**Spina Bifida Association
Albany/Capital District Chapter
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SBAAlbany102@AOL.com
www.SBAAlbany.org**

EDUCATION * SUPPORT * AWARENESS

Dear Friends:

I am excited to pass along a variety of chapter news. Much has been happening!

Spina Bifida Association of Albany/Capital District has been in existence for 14 years. Throughout this time, the services have been coordinated out of member's private homes. With the expansion of programs, it has become necessary for us to secure office space for the organization. We have identified space in Socha Plaza on Route 50 in Scotia. Our target date for move in is June 1st. We are in the process of exploring phones and email and will be sending out information with any changes in contact information. But for now, we know that our chapter will have it's own home!

As you know, along with a new house comes a whole wish list of items that will be needed to make it a home. You will find a wish list inside. I have been sending out letters to businesses that might be able to help with in-kind donations, but if you have a source that might be able to help with any of the items, please let us know! With the support of donations from businesses, we are hoping that we can keep our costs for these one-time-only purchases at a minimum, allowing us to continue to channel our funds toward the provision of services for individuals and families affected by Spina Bifida.

There are several important pieces inside that I ask you pay particular attention to:

- Saratoga Day At the Races – This will be a very important fundraiser for our chapter to help to support the activities and services. Please help to support it by volunteering to help, securing donations, participating or making a donation yourself.
- Freihofer's Community Walk – This is a great way for our teens to give back. Please encourage their participation. Everyone is welcome, but if you are unable to walk with us, please consider sponsoring either one of our teens, or me. I walk for the chapter each year.
- Make special note of the materials that are out from the lending library.

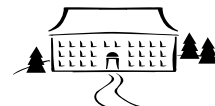
With that, I invite you to read on!

Karen Wentworth

Executive Director

Chapter News

Mohonk Mountain House Program



On April 21st, we had a group of over 50 people meet at Mohonk Mountain House in New Paltz. This included people from our chapter as well as a group who came to join us from the Nassau Chapter on Long Island. Participants spent the morning with Elaine Carlevaro, Certified Nutritionist. During the presentation, many of our younger participants were entertained by Mikaela and Crew who provided childcare. Thanks for playing!

After learning many tips about healthy eating, families were treated to a wonderful buffet lunch served by Mohonk staff. We were especially pleased when Elaine approved of the eating choices, indicating that we were all able to get a very healthy lunch from the options available.

After lunch, we went to the tennis courts for a clinic led by Jim Neal, the tennis coach who provides instructions in our program in Schenectady. We had several people who were new to the sport of wheelchair tennis, and 4 of them mentioned that they would be looking for opportunities to play in the future. Thanks, Jim, for sharing your love of the sport!

Lending Library

We have many materials that have been borrowed from our lending library for a lengthy period of time. ***If you have some of these, please pop them in the mail.*** We have had requests from families that we haven't been able to fill! Please check around your house for:

Adult Resources:

Delicate Threads: Friendships Between Children With & Without Special Needs...

Hydrocephalus: A Guide for Patients, Families, & Friends

Motherhood Magnified: Inspiring Stories of Insight & Lessons...

You Will Dream New Dreams: Inspiring Personal Stories...

Teens & Tweeners:

Crystal: Coping with Spina Bifida

Spinabilities: A Young Person's Guide to Spina Bifida

Taking Charge: Teenagers Talk About Life & Physical Disabilities

Picture Books:

All Kinds of Friends, Even Green

Andy Finds a Turtle

Danny & the Merry-Go-Round

Featherless

Patrick & Emma Lou



Saratoga Day At The Races! A Win-Win Event!!

Sunday, August 12, 2007

Our fundraising committee, chaired by Jim & Jennifer Gallagher, has been working hard to create a special day for our chapter.



Their plan?

1. Raise awareness about spina bifida in the community
2. Provide an opportunity for people from our chapter to get together with each other, including extended family and friends
3. Raise funds for our chapter.

Jim & Jennifer tell us that we can expect Corvettes and a race named for our chapter. Are you curious? We know from last year that it will be a day of fun!

You will be getting details about the events for the day soon.

Please mark your calendars and plan to participate.

Can you help the committee with some short term projects? Please call or email. The committee would really appreciate your help!

Freihofer's Community Walk

Saturday, June 2, 2007

8:00 AM

Brochures are enclosed. A group of us will be walking the course that day. Please join us!

If you are unable to attend, you can be there in spirit by sponsoring Karen Wentworth for her walk. You may send your sponsorship donation with a check made out to SBA of Albany/Capital District to 109 Spring Road, Scotia, NY 12302.

The Community Walk is held in conjunction with the Freihofer's Fun for Women at the Empire State Plaza in Albany. It is an opportunity for the community to support area non-profit organizations.

I will walk, rain or shine!



Preschool Family Program

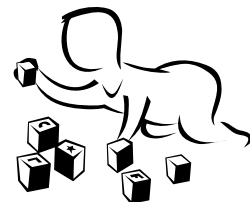
Saturday, June 2nd (following Freihofer's Community Walk)

Schedule: 9:15 AM Bagels & fruit

10:00 Talk with the Teens - Parents

(Childcare will be provided from 10 – 11:30)

11:30 Pizza – everyone



RSVP: Please send us your RSVP along with the number of adults attending & the number and age of children.

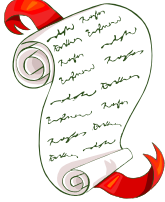
* Please submit a question that you have for the panel along with your RSVP. These questions will be used to get the discussion started. You will have the opportunity to ask other questions during the presentation.

* Each child should bring two toys or games to share during childcare.

Most parents have not experienced what it might be like to have a disability while growing up. We have several teens who have volunteered to participate in a panel to answer your questions. Do you have concerns about what you should be doing or preparing for to best help your child? Our teen panel would like to offer you their perspectives and insights about what has worked and been helpful to them.

Chapter Wish List

Our new office address will be 123 Saratoga Road, Bldg1-7. Because we have never before had office space, there are many needs/wants that we hope to fill through donations. Please look at the list below. If you have a contact that might be able to help fill that need or wish, please call or email and let us know.



- Vacuum cleaner
- Under counter refrigerator
- Microwave
- Bathroom cabinet
- Window blinds & valances
- TV – small, DVD, VCR (for lending library)
- Cable lock for laptop
- Phone & fax machine
- *Waste baskets
- *Cleaning bucket
- *Cleaning supplies
- *broom, dust pan, mop
- *Paper towels, toilet paper, tissues
- *Utility cart

Nominations Open for Chapter Board of Directors

Our nominating committee, chaired by Hali Holmes, is in the process of putting together a slate of offices that will be presented at the annual meeting October 26th, 7:30 PM at Double “H” Hole in the Woods. Are you interested in serving on the board or do you know someone who might be? Please call or email if you would like to nominate either yourself or someone else for a board of directors position. Thank you.

Scientists Growing Organs

Channel 7 ABC Chicago reported on a great story on The Wake Forest tissue growth project as it relates to Spina Bifida. They have successfully grown bladders from cells. The story is about Kaitlyne who has Spina Bifida. She is one of seven people in the world who has received a custom-made bladder.
<http://abclocal.go.com/wls/story?section=health&id=5165588>



ListSers Available!

In a recent survey by our national organization, Spina Bifida Association, they found that most who responded were not familiar with the ListSers, hosted by SBA, that are available to them.

- SB Parents ListServ** - The SB Parents Listserv is for any parent of a child who has spina bifida.
- Occulta ListServ** - This listserv is a networking opportunity for the Spina Bifida Occulta community.
- Youth and Adult Alliance (YAA) ListServ** - The YAA is a link for adults with spina bifida, young and old, to communicate with each other about a wide range of issues of common interest.
- YAA BLOG** - Link into the Spina Bifida Community. You'll meet fascinating people, learn about the latest treatments and research and find out about the most recent events that affect adults of all ages living and thriving with spina bifida. The YAA BLOG is updated regularly so visit often.
- Nursing & Health Care Professional's Council (NHCP) ListServ** - The purpose of this list is to provide an online discussion resource for nurses, nursing students, physical therapists, occupational therapists, and other health care personnel who are routinely involved in the treatment and care of individuals with spina bifida. You may want to share this information with your health care providers.

Subscription information is available at www.sbaa.org. This service is free!



Eclectic Women with Spina Bifida Telegroup

(Eclectic: to be made up of or gather from a variety of sources.)

Sponsored by
SBATSR

Spina Bifida Association Tri-State Region
Monthly Conference Call

Facilitator: Carla Heath, RN, MSN, FNP-C

Carla is a Certified Family Nurse Practitioner with personal experience of spina bifida, marriage, & motherhood and teaches holistic health workshops.

This telegroup is a peer support group for women with spina bifida who are mothers, married, working, interested in holistic health approaches, and/or were diagnosed with spina bifida later in life.

A telegroup is a professionally facilitated interactive support group which meets once monthly for one hour via telephone conference call. No special equipment is required. Simply dial in from your home phone. Registration is free but required. For non-SBATSR participants, the only cost is your long distance carrier's charges for your call or low-cost phone cards may be used. Dial-in information is sent to you prior to the telegroup session.

For further information, contact Betty McLaughlin at bmclaughlin@sbatsr.org or 856-825-0838.

Registration information requested:

Name Address Phone Email

My main interest(s) in this telegroup is:

Mail to: SBATSR* 84 Park Avenue, Suite G-106*
Flemington, NJ 08822 or info@sbatsr.org.

“Setting Your Sights Beyond High School: Strategies To Get What You NEED and Most of What You Want.”



Spina Bifida Association of Cincinnati announces registration is open for the next series Tele-Program - (Article in March/April Insights)

The Tele-Program, is about creating learning communities and social networks for teens and young adults. The purpose is to connect folks and increase personal effectiveness through facilitated discussions and shared experiences. The topics relate to transitioning to adult life and utilize adults with experience in the discussions. Participants "meet" over a toll free bridge line for one hour a week for nine weeks. The next series will begin in early May. To register or further information call Sharon Sellet @ 513-467-9292 or email

sharon@perceptioncheck.com

**UnitedHealthcare Children's Foundation
to Offer Medical Assistance Grants to Families Nationwide**

The UnitedHealthcare Children's Foundation (UHCCF) is now offering support to meet the needs of children nationwide with assistance grants for medical services not fully covered by health insurance.

Parents and caretakers across the country will be eligible to apply for grants of up to \$5,000 for health care services that will help improve their children's health and quality of life. Examples of the types of medical services covered by UHCCF grants include: speech therapy, physical therapy and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids and eyeglasses; and orthodontia and dental treatments.

"The UnitedHealthcare Children's Foundation has already helped more than 375 families and provided nearly \$1 million in financial assistance," said UHCCF president Matt Peterson. "We are excited about the expansion of the program, and look forward to the opportunity to help many more children access health care services that will enhance their health and quality of life."

To be eligible for UHCCF grants, children must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States and be covered by a commercial health insurance plan.

The UnitedHealthcare Children's Foundation is a nonprofit 501(c)(3) organization that strives to enhance either the clinical condition or quality of life of children who have health care needs not fully covered by commercial insurance. The Foundation provides grants of up to \$5,000 for costs associated with medical services and equipment. Foundation funding is provided by contributions from employees of UnitedHealth Group as well as individuals and corporations. To donate or learn more, please visit www.uhccf.org.

Special Needs Estate Planner

New topics provided by
Jones & Wilcenski PLLC are:

"What it Means to have a Disability" (referring to potential legal or work circumstances.)
"Employment and Individuals with Disabilities"

Partnership for Prescription Assistance

The Partnership for Prescription Assistance (PPA) brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free.

SBA is a member of PPA. Every state has a PPA initiative working to help people with their medications. We encourage you to share this information with your members.

Advise them to know the names of the medicines they take and speak with a trained specialist available to answer their questions and help them apply.

For more information on PPA or to find out who qualifies, visit www.pparx.org or call 888-4PPA-NOW.



Young Artists with Disabilities Ages 16-25: Enter National Juried Exhibition

U.S. artists ages 16-25 with physical, cognitive, or mental disabilities are invited to enter a national juried exhibition, sponsored by VSA arts and Volkswagen of America. Fifteen prizes ranging in value from \$2,000-\$20,000 will be awarded. Both representational and abstract work is welcome. This year's theme is: "What moves you to create? Can you pinpoint a force that motivates you to express your artistic vision? Is there a particular catalyst or compulsion that sustains your creative energy?" Entry deadline: July 6, 2007.

<http://www.vsarts.org/PreBuilt/showcase/gallery/exhibits/vw/2007/>

Young Disability Activists: Complete a Survey on Future Directions for the Disability Rights Movement

A group of young disability activists is working on a presentation for the National Council on Independent Living conference, where they will share youths' ideas for future directions for the Disability Rights Movement. To gather those ideas, they've created a brief (10-25 minutes) Web survey for young disability activists. E-mail surveydisculture@gmail.com if you have any questions about the survey or if you want to be part of an upcoming conference call to talk more about disability culture and disability community. Survey completion deadline: May 20, 2007.

<http://www.surveymonkey.com/s.asp?u=334633619052>

Promoting Health Care Transition for Adolescents with Special Health Care Needs and Disabilities (2007) (Book)

This book seeks to smooth the transition from pediatric care to adult medical care for youth with special health care needs. It helps readers improve their collaboration with other professionals to ensure coordinated care and services for youth, skillfully assess individual medical and health care needs, develop workable health care transition plans, ensure that transition outcomes match the goals and desires of the individual, help families locate and select adult medical and health care providers, and help youth secure health-related accommodations in school and at work.

<http://www.brookespublishing.com/store/books/betz-68608/>

"Portions of this e-mail newsletter were excerpted from the National Center on Secondary Education and Transition E-News, which can be found at

[http://www.ncset.org/enews/.](http://www.ncset.org/enews/)

Spina Bifida Association of Albany/Capital District does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or contents of any product or service mentioned herein. The information provided in this newsletter is for informational, educational and entertainment purposes only. It is not intended as medical or professional advice.

Folic Acid Now

These websites might have some helpful information about how you can supplement your diet with folic acid.

<http://www.cdc.gov/ncbddd/folicacid/cereals.htm> (fortified cereals)

<http://www.folicacidnow.net/foodChart.html> (food lists)

The following are the recommendations regarding folic acid from Spina Bifida Association:

All women of childbearing age should take a vitamin with 400 micrograms (mcg) folic acid every day – even when you're not planning to become pregnant. (This amount is also written as 0.4 milligrams (MG)).

If you are at a higher risk of a Spina Bifida affected pregnancy and you are thinking about becoming pregnant, you need a higher dose of folic acid.

To reduce your risk, you should take 4000 micrograms (mcg) of folic acid by prescription for 1 to 3 months before becoming pregnant. (This amount is also written as 4.0 Milligrams (mg)). Please see your health care provider.

Do not take this extra folic acid by taking more multivitamins because too much of some of the other vitamins could harm you and your baby.

The World Is Theirs by: **Linda S. Radzik**



When buildings are built with doors extra wide,
So that all people can come inside,
When all children are welcome to come and play,
Not just those who look one way,
When those with braces, and walkers, and wheels,
Can join right in with typical peers,
Then all God's children will come to know,
The world is theirs, wherever they go.

When hearts are open with love inside,
So that every child can live with pride,
When all children are welcome to come and share,
Not just those for whom we care,
When those in our block, our town, our state,
Can have enough to fill their plate,
Then all God's children will come to know,
The world is theirs, wherever they go.

Web Site Provides Useful Tips For Travelers with Disabilities



The Society for Accessible Travel and Hospitality (SATH) offers a wonderful Web site packed with resources, helpful information, and tips for disabled travelers. From traveling by air with a wheelchair or service animal to disability rights and regulations, this site is a great aid in trip planning. SATH's Web site can be accessed at www.sath.org.

The Special Mother by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year nearly 100,000 women will become mothers of handicapped children.

Did you ever wonder how mothers of handicapped children are chosen? Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth; son. Patron saint...give her Gerard. He's used to profanity."

"Forrest, Marjorie; daughter. Patron saint, Cecelia."

"Rutledge, Carrie; twins. Patron saint, Matthew."

Finally He passes a name to an angel and smiles, "Give her a handicapped child." The angel is curious. "Why this one God? She's so happy."

"Exactly," smiles God, "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it." "I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has her own world. She has to make her live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you."

God smiles, "No matter, I can fix that. This one is perfect -she has just enough selfishness."

The angel gasps - "selfishness? is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a "spoken word". She will never consider a "step" ordinary.

When her child says "Momma" for the first time, she will be present at a miracle, and will know it!" "I will permit her to see clearly the things I see...ignorance, cruelty, prejudice....and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side".

"And what about her Patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."

Spina Bitida Association of Albany/Capital District
109 Spring Road
Scotia, NY 12302

Mark Your Calendars!

SBA of Albany/Capital District moves into offices!

Freihofer's Community Walk

Preschool Family Program

(following community walk – see inside for schedule)

SBA national conference, Louisville, KY

Lime Rock Race Track

Jeannette Udway, longtime board member, drives with our logo!

Saratoga Day at the Races

Annual Meeting

Double "H" Camping Weekend

June 1st

Saturday, June 2nd 8:00 AM

Saturday, June 2nd 9:00 – 12:15

June 24th – 27th

July 28th

Sunday, August 12th

October 26th 7:30 PM

October 26th – 28th



Teen Support Group

Accessible Tennis Lessons

Central Park, Schenectady. Please call ahead for information.

Monthly, Saturdays, call for information

Most Saturdays, 3 – 4:30 PM

Reminder:

Please return borrowed materials to our Lending Library when finished with them.

Nominations open for Chapter Board of Directors