

Spina Bifida

NEWS

Albany/ Capital District Chapter

To Use

109 Spring Road, Scotia, NY 12302
(518) 399-9151

EDUCATION * SUPPORT * AWARENESS

CALENDAR OF EVENTS

Saturday, October 13, 2001 3 - 5 PM

Guest Speaker:

Dr. Barry Kogan, Pediatric Urologist

Dr. Kogan will speak regarding urologic difficulties & testing with Spina Bifida.

LOOKING AHEAD!

Saturday, December 8th, 2001

3 - 5 PM "Holiday Party"

Saturday, February 9th, 2002

3 - 5 PM Guest Speaker

Saturday, April 6th, 2002

3 - 5 PM Guest Speaker

PRESIDENTS CORNER

It's that time again... getting ready for the back-to-school surge of activities and the calendar filling with events. Get ready to keep track of more dates. We are trying to plan on group meetings for the months of October, December, February and April. Stay tuned for the dates and speakers planned. We are also continuing with the pre-teen/teen support group once a month, and will soon sponsor an adult support group. Remember also that we have a loan closet of equipment (crutches, walkers, wheelchairs, etc.). If you need to borrow anything, call the chapter for more information. We are also expanding our "lending library" of books, tapes and a variety of conference information on SB. This year we were able to send a delegate to the national conference in New Orleans. Look for Jeanne's comments and experiences within the newsletter. She brought back some wonderful information.

On a "medical" note we thought it would be a good time to provide reminders on ways to keep up with the many necessary appointments people with SB must have. With the Albany Medical Center Myelo Clinic now closed, it has been increasingly more difficult to remember, coordinate and schedule appointments. We have found it helpful to keep a 3-ring binder for medical information, etc. with sections available for Urology, Neurosurgery, Orthopedics, Therapy, etc. You can track appointments, x-rays, tests and results, jot questions for doctors and track when future tests should be. Without a nurse coordinator assisting with this, our responsibilities continue to grow. It is imperative for the continued good health of people with SB that we keep up with the necessary medical care. On average, children with SB should have an annual physical from their healthcare provider, annual or semi-annual renal ultrasounds, urodynamic testing every 2 years, 6 - 12 month monitoring from Orthopedics with annual or semi-annual x-rays of hips/spine and periodic monitoring from neurosurgery. Adults should consult with their health care specialists concerning their schedule of care. Be aware of the neurological signs of shunt failure (irritability, headache, vomiting, visual disturbances) and tethered cord (back pain, leg weakness, changes in bowel/bladder functioning, increase in scoliosis). Contact your specialist immediately if you suspect any of these conditions.

The topic of the AMCH myelo clinic closing and the loss of the nurse coordinator position has been a frequent discussion among our board members. We have had discussions with a few doctors at AMCH regarding the importance of the Myelo clinic and our concerns. It is encouraging to note that these doctors have not given up on this very important program and are open to our input, so please share any thoughts, concerns or suggestions you may have.

Chris Darby-King, Helen Eggenberger, Co-Presidents

TENNIS ANYONE?

The SAFE (Sports Are For Everyone) program of Clifton Park will be holding 5 sessions of tennis instruction for any child with Spina Bifida.

Who: Any child with Spina Bifida interested in learning to play tennis

What: Tennis instruction provided by tennis professionals

When: Saturdays, September 22, 29, October 3, 10, 17, (rain date October 27)

Time: 10:00 AM

Where: Tennis Courts in Central Park, Schenectady

Cost: Free to participants.

Questions: Call the local chapter at 399-9151 for information and to register!

Pre-Registration Is Required. Please call in advance. The program has a limited number of spaces available.

This program is being sponsored by the Albany/Capital District Chapter of the Spina Bifida Association. Additional lessons are being planned for next spring. Watch our newsletter for further information.

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CHECK OUT THESE WEBSITES!!

www.merckhomeedition.com. Provides fast, accurate medical information in easy to understand language, and users can also search the site. The interactive elements, including videos and animation, explain complex medical information in ways that no printed book can.

www.clubs.yahoo.com/clubs/spinabifidacentral Club with 801 members, mostly of families living with Spina Bifida; read about others' concerns about Spina Bifida or ask your own questions; good place to make some new friends online that truly understand what our lives are like.

www.electriciti.com/spinal/. Please visit this site to learn about Dr. Ramirez and Embryonic Cell Transplant Therapy. The site covers many aspects of the procedure, including explanations for chosen locations, expected costs, success rates and frequently asked questions.

www.KidsHealth.org. Written by pediatricians, nurses, and health educators, KidsHealth is a powerful information engine for children's health care and treatment. Designed for parents and kids, it is an easy, fun way to obtain information about important medical and surgical conditions, "scary" lab tests, behavior and emotions, common infections diseases, nutrition and fitness, valuable community resources and more.

www.lekotek.org. Visit the National Lekotek Center for assistance in choosing toys for kids with disabilities. The nonprofit organization selects and evaluates the toys included in the Toys "R" Us Guide for Differently-Abled kids and is dedicated to making play accessible for children with disabilities.

www.disabledperson.com. Is an online magazine and resource site that is geared specifically toward the person with disabilities.

Reprinted from SBADV News, the newsletter of the SBA of the Delaware Valley, PA.

Adult Support Group Albany/Capital District Chapter

We continue to hear interest expressed from adults with Spina Bifida for an adult support group. This could be a combination of support, education, sharing of resources, and social activities. Please share your ideas about what might be helpful to you! If you have questions, call Chris Darby-King at 399-9151 or e-mail at Rexdar109@AOL.com. If you might be interested, but are unable to attend the next meeting, please call and let us know!

Nickelodeon Network Airs Cartoon Series Featuring a 13-year old in a Wheelchair

In October of 2000 the Nickelodeon television network launched a groundbreaking animated series. The cartoon features a 13-year old boy named Pelswick who uses a wheelchair and demands to be treated like everyone else. Pelswick, a quadriplegic who enjoys poking fun at the odd predicaments he faces daily, shatters the stereotypical view about kids with disabilities. The show's creator and author, syndicated cartoonist John Callahan, uses a wheelchair himself as a result of a spinal cord injury. Pelswick can be seen Saturday evenings at 5:00pm and Sunday mornings at 6:30 am on Nickelodeon.

Reprinted from PERCEPTIONS, the newsletter of the SBA of Nebraska, Inc.

Orthopedic Shoes

Pedors Shoes Manufactures an orthopedic shoe that stretches to accommodate forefoot abnormalities. The web site is at www.pedors.com. For information, call 1-800-750-6729, and ask for Stephen O'Hare.

Reprinted from SBADV News, the newsletter of the SBA of the Delaware Valley, PA.

ODOR GONE

Home Delivery Incontinent Supplies Co. Inc. has a wide range of products and a knowledgeable and compassionate staff. "Fresh Again" is a product that should improve your life. It eliminates urine and excretory odors and can be sprayed directly onto absorbent products, bedpans, toilets, etc. It's water based and non-irritating to your skin. An 8-ounce bottle is \$6.64. To order, call (800)2MY-HOME. HDIS is also happy to send a free sample or two of its absorbent products.

Reprinted from SBADV News, the newsletter of the SBA of the Delaware Valley, PA.

Dear Families:

I sit here trying to gather my thoughts and to capture in words my experience as a first time delegate attending my first national conference for the Spina Bifida Association of America. The wealth of information I received came from going out and introducing myself and telling my individual story. It was incredibly enlightening and overwhelming at the same time. As a 31 year old adult with SB, I have "dealt" with my condition but have been unable to consider myself "disabled". I have come to realize that SB is, in its simplest of terms, a disability.

It was very exciting for me to see so many new faces all very willing to share their stories of living with SB. We all have limitations, we all face ongoing issues and complications whether it be physical or emotional. That is what makes this conference so outstanding yet so overwhelming. It was so comforting to realize that I'm not alone; that there are hundreds, even thousands more individuals "just like me".

As I reflect on this year's theme for the conference, "The Parade of Possibilities", I now realize the full impact of this statement. This conference has given me the opportunity to see the limitless possibilities; possibilities within myself as an individual with SB, and the possibilities we have as an organization as a whole.

As a delegate, I had the privilege to sit in on and vote for the new chair of the national organization. I saw first hand how the organization functions on the national level versus the local level. All of the members of the board up to and including the recently appointed CEO, Cindy Brownstein, all bring tremendous desire and expertise to the table. They are dedicated to keeping the SBAA as a whole alive and flourishing in the future.

It is an exciting time for the organization as new task forces have been formed to push SB into the forefront of everyone's minds within the community as a whole. All in all, it was incredibly freeing to experience the comfort I felt as I joined forces with a very powerful and meaningful group of people. It was an experience I will not soon forget.

Sincerely,

Jeanne Litke

You have received this newsletter through the kindness of Dr. Malone. Due to the rules of confidentiality, we are unable to access this mailing list. ***Therefore, in order that we might develop a mailing list for the The Albany/Capital District Chapter of the Spina Bifida Association, we ask that you fill out the information below and return in the enclosed self-addressed envelope.*** With your assistance in this matter, we will be able to continue to serve you with future mailings from our organization. Thank you.



Name _____

Street Address _____

City/State _____

Zip Code _____

E-Mail _____