

Spina Bifida

NEWS To Use

Albany/Capital District Chapter
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Dear Families,

It has repeatedly and more frequently come to our attention that many families are unaware of some of the medical testing that people who have Spina Bifida should complete in order to best prevent potential health concerns, many of them serious. Therefore, we are sending out this information for you to seriously review and recommending that you speak to your medical providers. ***Please take the time to review this now. You should address your questions or concerns regarding these matters with your medical provider.***

We hope that the information is helpful.

Karen Wentworth

Administrative Director

CRITICAL HEALTH RELATED REMINDERS

It's time to offer reminders on ways to keep up with the many necessary appointments people with SB must have. With no myelo clinic in our area, it can be difficult to remember, coordinate and schedule appointments. Some people 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, make notes of questions for doctors and track when future tests should be. Without a nurse coordinator assisting with this, parent and family responsibilities and actions are critical. It is imperative for the continued good health of children and family members who have SB that we keep up with the necessary medical care. On average, children with SB should have the following:

1. annual physical from their healthcare provider
2. annual renal ultrasound
3. urodynamic testing baseline at 2 or 3 years
4. Urodynamic testing every 2 years after the baseline
5. 6 to 12 month monitoring from orthopedics with periodic x-rays of hips & spine
6. 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.



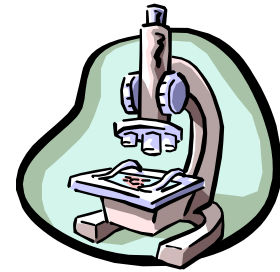
The Care Notebook (2003) (Guidebook)



The Care Notebook and Care Organizer are tools for families who have children with special health care needs. Families use Care Notebooks to keep track of important information about their child's health and care. This makes it easier to find and share key information with their child's care team. It was created by The Center for Children with Special Needs. For more information, visit their website at:
<http://www.cshcn.org/resources/CareNtbk.htm>.

LOCAL RESEARCH STUDY

Karla Giramonti, FNP and Barry Kogan, MC are doing a study to test whether anticholinergic medications have an effect on attention and short-term memory in children. Oxybutynin (the most commonly used anticholinergic medication) has been used for many years in children and is critically important for some children to lower bladder pressures and prevent kidney damage and incontinence. However, in the elderly population, anticholinergics have been known to cause short term memory problems in some patients. This side effect, although rare in the elderly population, has never been evaluated in children. Dr. Kogan and Ms. Giramonti don't believe there is a problem with anticholinergic medications in children, but they don't know for sure.



The study will involve testing your child for a baseline of memory recall. Following this, your child will be placed on either an anticholinergic medication (either Ditropan or the new alternative, Detrol), or a sugar pill. To insure that the study is fair, neither you or the researchers (Dr. Kogan and Karla Giramonti) will know which pill the participant is taking until the end of the study. A second educational test will be done after two weeks and the medication will be switched (if your child started with a sugar pill, he/she will be given the medication; if they got the medication first, they will be given the sugar pill). After a third educational test, Dr. Kogan and Ms. Giramonti will study the results to determine the effects of the medication. Finally, after testing a number of children, they will be able to determine if the medication causes memory problems. Although they don't know of any definite problems, they feel this is an important study. If you are able to help them (and at the same time, see about the effects for your child), or if you have any questions regarding this study, please contact them at their office.

Dr. Barry Kogan
Karla Giramonti, FNP

The Urological Institute of Northeastern New York
23-25 Hackett Blvd
Albany, NY 12208

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“DOUBLE H” HOLE IN THE WOODS WEEKEND CAMPING TRIP

DATE: October 29 - 31
TIME: 6:00 PM Friday through Sunday noon
Place: Double H Hole in the Woods
 97 Hidden Valley Road
 Lake Luzerne, NY
 * Double H is approximately 1 hour north of Albany
WHO: Families who have members who have Spina Bifida
ACTIVITIES: high & low ropes course, indoor swimming, hiking, fishing, boating, arts & crafts, Halloween costume party & fall activities
ACCOMMODATIONS: Cabins equipped to hold 2 to 4 people. Cabin assignments will be by family.
FEE: Double H does not charge a fee for use of their facilities. They depend upon private and corporate donations to cover their expenses. They are a not-for-profit organization.
Questions? Call 399-9151 or email us at SBAAlbany102@aol.com
RSVP required: *Please send in the form below by Friday, October 8, 2004.*

*We are looking forward to having a great weekend together,
to enjoy the beautiful Adirondacks in the fall, with terrific company!*



To make a reservation, please send the following information **by October 8, 2004.**

Name of person with SB _____ **age** _____

Address _____

Phone _____ **Email** _____

Parent/Adult Support People

1. _____

2. _____

Names & Ages of Siblings

1. _____ Age _____

2. _____ Age _____

3. _____ Age _____

4. _____ Age _____

Special dietary concerns: _____

of vegetarian menus required _____

of adults interested in 10 minute chair massage _____

Child care is available during massage session.

Child care needed: # of children _____ ages _____

See next page for brief description of chair massage.

Mail form to: SBA: Albany/Capital District Chapter
109 Spring Road
Scotia, NY 12302

Chair massage is done in a comfortable chair designed especially for this purpose. It is done with the client fully clothed. The Therapist usually begins with a series of gentle “holds” or “laying on of hands” to help relax the client and release tension. The Therapist massages the shoulders, neck and back and depending on the Therapist and the client’s wishes; the head, arms and/or hands. No oil or cream is used. The Therapist is happy to accommodate individual needs and depth of pressure. Because the client is clothed, the techniques are a little different than a massage without clothing – there is more Kneading and Compression than long fluid sweeping. Just 10 minutes of chair massage can reduce tension, loosen tight muscles, induce relaxation, and increase blood flow - thereby increasing immune function. It also feels GOOD!

Massages will be given by Licensed Massage Therapists Margaret Cernik and Jane S. Gray of Healing Path Massage, 670 Franklin Street, Schenectady, NY 12305. The Albany/Capital District Chapter of the Spina Bifida Association will be paying for related fees.

Childcare will be provided *during your massage session* if you need it. Please reserve ahead.



Frequently asked question: Is there a fee for this weekend?

Because of the financial toll that falls upon families dealing with childhood illnesses, there is no cost to any of the families who attend this weekend at the ranch. Contributions from individuals, corporations, and foundations fund the cost of operating the camp. Last year our chapter made a gift to Double “H” of a ski sponsorship as a “thank you” for the terrific weekend that our members were able to enjoy at the ranch. Our board of directors has not yet decided upon this year’s gift from our organization.

Several families asked me what they might do to express their gratefulness to the ranch. If you would like to offer something, you can either make a monetary donation or review the items on their wish list at www.doublehranch.org. *While any gift or donations are always greatly appreciated, please understand that this is not required.*

IT'S TIME TO MARK YOUR CALENDARS!

TEEN SUPPORT GROUP

DATES: October 16 November 20 December 18
TIME: 10—11:30 AM
LOCATION: Colonie Community Center
1653 Central Ave
Albany

WHEELCHAIR TENNIS LESSONS

DATES & TIME: To be announced
LOCATION: Schenectady Racquet Club
2699 Curry Road
Schenectady

CROSSGATES MALL BOOTH

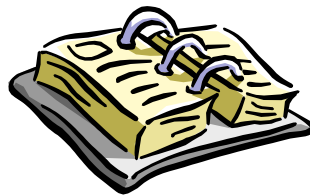
Public education and awareness
DATE: October 9, 2004
TIME: 10 AM to 6 PM

DANCE LESSONS for STAND-UP & SIT-DOWN (WHEELCHAIR) DANCERS

Conway's Circle of Performing Arts
Corner of Parkwood & Rugby Road, Schenectady
Currently a class is held Monday evenings from 7 to 8 PM.
Call 377-3929 for information.

DOUBLE "H" HOLE IN THE WOODS RANCH WEEKEND

DATE & TIME: Friday, October 29th, 6 PM to October 31st at Noon
See inside for details and reservation form.



**PLEASE OPEN PROMPTLY
TIME SENSITIVE MATERIALS ENCLOSED**

*******CRITICAL HEALTH REMINDERS*******

DOUBLE "H" RESERVATIONS DUE BY FRIDAY, OCTOBER 8, 2004

RESERVATION FORM ENCLOSED



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