

Newsletter

Winter 2005



Spina Bifida and Hydrocephalus
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Take Action - Conference 2006

Mark your calendars: September 15-17, 2006 you will want to be in Edmonton! In conjunction with the SBHANA, we are organising the first ever provincial conference on spina bifida and hydrocephalus.

At the conference, we will be "Taking Action" and sharing the concerns that unite all of us living with spina bifida and / or hydrocephalus.

This conference will have something for the whole family:

- Information sessions including orthopedics, urology, neurosurgery, sex, adult health issues, employment for the differently abled, latex allergies and learning disabilities
- A disability expo / trade show for vendors of equipment and medical supplies throughout Alberta
- Dinner and dance, with live entertainment
- Day camp for kids
- Ideas on how you can take action in your everyday life: recreation, advocacy, education, and more.

The Fantasyland Hotel will be our host, and information on rates and registration will be coming later. Check our website for updates - you won't want to miss it.

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Wheelchair Sports Day at U of C: January 29th

Are you interested in wheelchair racing, handcycling, basketball, sledge hockey or any other wheelchair sport? Visit Wheelchair Sports Alberta on Sports Day at the University of Calgary: January 29th, 2005 in the Gold Gym from 1 to 5 pm. Watch demonstrations of various sports, view videos, or try the sport yourself.

The views and ideas expressed in this newsletter do not necessarily reflect the views and / or ideas of the SBHASA. This newsletter's content is for educational and informational purposes only. It is not intended to replace, and should not be interpreted or relied upon as, medical or professional advice.

President's Message

Happy New Year!

I hope that everyone had a good holiday season and is looking forward to a great new year. I am looking forward to some exciting things in the new year. I would like to get some new members (and some old ones) on the board and helping to direct our efforts.

One new thing I personally would like to see happen this year is a group get together for our members: maybe a picnic in the summer, or a day at the zoo. Our membership is tied together because we are all affected in some way by spina bifida or hydrocephalus. We should share some of our stories and experiences with each other, learn from each other and grow to be a strong well directed organisation.



It is my hope that over the next year I get to meet as many of the members as possible. Please think about

Executive Committee:

Douglas O'Muir
President

Joe Dzurilla
1st Vice-President

Anthea Crewe
2nd Vice-President

Gerda McGregor
Treasurer

Sherri O'Muir
Secretary

Eleanor Reimer
Member at Large

Debbie Richter
Past President

getting involved in some way. We are always looking for new ideas on the board: an adult or young adult board member with spina bifida would definitely give us a new perspective on things.

Please contact me through the SBHASA email or voice mail line if you have anything you would like to discuss.

Have a safe and happy winter,

Douglas O'Muir

Membership Renewals

It's that time of year again. Please be sure to renew your SBHASA membership for 2005. The membership fee is still only \$10, and you get these great benefits with your paid membership:

- 1 SBHASA newsletter.
- 2 Access to funding programs.
- 3 Access to bursary program.
- 4 Join the Board of Directors.
- 5 Access to educational resources.
- 6 Automatic membership in the Spina Bifida and Hydrocephalus Association of Canada.

Special Offer in 2005: Along with your membership you may purchase a copy of *When Your Child has Learning Differences: a survival guide for parents* for only \$10, if you renew before February 15th, 2005.

Book contents:

- Chapter 1 What is LD
- Chapter 2 Why does my child have LD
- Chapter 3 Early signs of LD
- Chapter 4 Your child's legal rights
- Chapter 5 Your legal rights as a parent
- Chapter 6 How LD can affect your child
- Chapter 7 How LD can affect your family
- Chapter 8 Coping with Curious Friends, "Helpful" Relatives and Nosy Strangers
- Chapter 9 Do's and Don'ts for helping your child
- Chapter 10 Ways to work with the school
- Chapter 11 Getting help outside of school
- Chapter 12 Looking toward the future

Please complete the membership form on the opposite page, and send it to our office before February 15th, 2005 along with your membership fee in order to qualify for this special offer.

www.sbhasa.ca



2005 SBHASA MEMBERSHIP FORM

To join the SBHASA or renew your current membership, please complete this form and mail it to our office along with your payment. The membership fee is \$10.00 per year, from January 1 to December 31, 2005.

As a member you will receive the SBHASA newsletter and have access to resource and educational materials. You are also automatically made a member of the national association (SBHAC). Members in good standing with Spina Bifida and/or Hydrocephalus who live in Southern Alberta will have access to the association's funding programs and scholarship program.

Special Offer in 2005: Along with your membership you may purchase a copy of When Your Child has Learning Differences for only \$10, if you renew before February 15, 2005.

Date: _____

_____ I am renewing my membership _____ I would like to join the association

_____ I would like to join/renew but am not able to pay the membership fee

_____ Enclosed is a general donation in the amount of \$ _____

_____ Send me a copy of When Your Child has Learning Disabilities for an additional \$10 (must renew before Jan 30/05)

Please Print:

Name(s) _____
Last First

Last First

Address _____

City _____ Postal Code _____

Telephone _____ Fax _____

Email _____

Type of Membership (please check one)

_____ Parent of child with Spina Bifida and/or Hydrocephalus

Name of Child _____ Date of birth _____

_____ Individual with Spina Bifida and/or Hydrocephalus Date of birth _____

_____ Support person (relative, friend)

_____ Professional caregiver (medical, social worker, educator, etc.)

I can volunteer to help the association and other families:

_____ Executive _____ Committees _____ Phoning

_____ Fundraising _____ Special Events _____ Other _____

I would like to be phoned about upcoming events: _____ Yes _____ No

Wheelchair Basketball

Are you interested in playing wheelchair basketball?

The drop in wheelchair basketball program is still running at Mount Royal College in the Stanley Gym. The winter session will go from January 18 to April 12, 2005.

Wheelchair basketball takes place from 6 - 7:30pm on Tuesday days. The gym will be split between the junior and adult programs.

There was a great turn out for Junior Program in the fall, but there is always room for more! No special equipment is required; come on down to MRC to give it a try, or contact Diane if you are interested in finding out more (dsorensen@forzani.com).



Sledge Hockey

Ever thought about giving sledge hockey a try?

The SBHASA sponsors a team in Calgary, and all our members are welcome to join - there is no registration fee as long as your SBHASA membership is up to date.

Sledges and sticks are provided, but you will need to bring your own protective gear (helmet, gloves, etc). The team practices at the Stew Hendry Arena (814 - 13th Avenue NE) every second Saturday from October through April.

Practice dates for the remainder of this season are as follows:

January 8th & 15th
February 5th & 19th
March 5th & 19th, 26th

Check out our website for more information or updates on sledge hockey.

Wheelchair Curling

A truly Canadian sport for the differently abled has started in Calgary - wheelchair curling. No special equipment is required as the group has 8 brand new delivery sticks for participants to share.

Fifteen people tried out the premiere session of the new league back in November 2004, and there have been 2 more sessions since.

Program coordinator Ernie Cumerford would like to set up a fun league which would curl on a regular basis at one of the clubs in Calgary. He is also looking for people who want to be more competitive, who can be placed on a competition team with a coach. They would then begin to prepare to compete against the teams from Edmonton to represent Alberta in the Canadian Wheelchair Curling Championships.

For more information, contact Ernie at 236-3239 or emjcomerford@shaw.ca, or check our website (www.sbhasa.ca) for program updates.



Hydrocephalus and Learning

Many children and teenagers with hydrocephalus will be less 'street-wise' than others the same age. Very many will be lacking in self-confidence, although their 'chattiness' may disguise this. Children and young adults with hydrocephalus may appear to have difficulties in:

- focusing on their work;
- organising themselves;
- figuring out how 'good' their work is.

These problems are related to working memory skills. They may be overlooked when a child has been assessed as having 'learning difficulties' because it is sometimes presumed that children with moderate or severe learning difficulties cannot learn to do these things.

Working memory refers to short-term memory (both for speech, and for mental 'pictures'). It also refers to the way we can focus on things we need to think about, and organise our thoughts. (This is called 'executive' thinking).

Self-confidence is important for learning. Children with hydrocephalus are likely to have a poor self-image in terms of physical abilities. They should be encouraged to learn how to do different tasks for themselves, and for the family, in order to boost their self-esteem. They need to be able to think 'I can'. Personal experience of working with some of these children suggests that they can develop more confidence in themselves, and that this does have an effect on motivation and 'stickability'.

Other difficulties may include:

- hand-writing;
- copying from the blackboard;
- remembering instructions;
- taking part in class discussions and listening to stories;
- predicting 'what will happen next' in a story, or explaining why something happened;
- talking about their feelings, or giving their own views about different things;
- acquiring reading and spelling skills.

Adapted from "Hydrocephalus and Literacy and Thinking Skills", ASBAH. View the full article online at:

http://www.asbah.org/Downloads/H-inf_sh_7.pdf

Accessible Travel

TASC International is a new web-based travel information service for people with disabilities. The service is designed to help travellers locate travel services that meet their specific needs.

The TASC website has been designed to give members the opportunity to create a unique personal profile. This information is used to find hotels that suit their particular needs.

More than 150 categories in the website's database allow members to indicate their preferences for everything - for example door widths, room for lifts, and roll-in showers. And like other online travel directories, services can be selected based on price, location and other features.

While hotels supply their own information to the database, TASC will hire local people from disability organisations to verify accessibility data.

The database also contains information about restaurants, attractions, tours, transportation, and medical supply companies in various North American cities. Cruise ship lines will eventually be added.

For more information, please visit TASC International on the web: www.tascinternational.org.

Adapted from Total Access Magazine, Winter 2004

Accessible Housing: Five Great Barrier Free Design Websites

Architect Ron Wickman gives his list of top online resources in the hope that they may help you renovate for accessibility or design your next barrier-free home (adapted from Total Access, Winter 2004).

www.design.ncsu.edu/cud

This is the website for The Center for Universal Design located at NC State University in Raleigh, North Carolina. Their mission is "to improve the built environment and related products for all users by impacting change in policies and procedures through research, information, training, and design assistance." There's so much information available here - in fact, it's somewhat overwhelming. Do you want to purchase books relating to universal design? Produce accessible house plans? Know how to construct a curbless shower? Visit this website for the answers to these questions and more.



www.cmhc.ca

The Canada Mortgage and Housing Corporation (CMHC) website is really Canada's equivalent to the Center for Universal Design website. However, CMHC does not just focus on universal design; rather its research looks to improve the quality and affordability of all housing. Nevertheless, there is plenty of disability specific information here with a distinctly Canadian flavour.

www.adaptenv.org

Adaptive Environments, a non-profit organisation located in Boston, offers this excellent website for those interested in design. The website advances the role of design in expanding opportunity and enhancing experience for people of all ages and abilities. Adaptive Environments' work balances expertise in legally required accessibility with promotion of best practices in universal design. Projects vary from local to international. Lots of online resources and links can be found here.

www.ap.buffalo.edu/idea

This is the website for IDEA (the Center for Inclusive Design and Environmental Access) located in the School of Architecture and Planning at the University of Buffalo in New York. No organisation like this exists in Canada. IDEA is dedicated to improving the design of environments and products by making them more usable, safer and appealing to people with a wide range of abilities. Through its website, IDEA provides resources and technical expertise in architecture, product design, facilities management and more.

www.nahbrc.org

The NAHB Research Center is located in the US. Its website is really a directory of accessible building products, listed in the following categories: kitchen and laundry; bathroom, doors, windows, and assistive hardware; climate control; home automation; plumbing systems; ramps; stair lifts and elevators; and accessible house plans. Very practical, useful stuff here.

Other accessibility sites:

Americans with Disabilities Act
www.ada.gov

United Nations, Persons with Disabilities
www.un.org/esa/socdev/enable

Disability Weblinks
www.disabilityweblinks.ca

Canadian Paraplegic Association
www.canparaplegic.org

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Persons with Disabilities Online

The federal government has launched a new website for disabled persons, which will act as an access point for information on disability-related programs and services.

The site's mission is to provide access to information from a variety of sources; enhance the ability of Persons with Disabilities to use Internet technology; improve access to services that strengthen the quality of life for Persons with Disabilities; and serve as a model of accessibility.

Initiatives developed for Persons with Disabilities Online include:

Access to Travel

Led by Transport Canada, this portal provides information on accessible transportation for travel both in and outside of Canada with the goal of making accessible transportation easy and enjoyable.

Assistive Computer Technologies

Led by Industry Canada, this site assists Persons with Disabilities and employers to find information and resources on assistive computer technologies, including links to information on tools and suppliers.

For more information, visit them on the web:

www.pwd-online.ca

Education: What's New and What's Happening

Education for Life Bursary

The Alberta Committee of Citizens with Disabilities (ACCD) awards a bursary to persons with disabilities at the entry level or attempting one course to begin their post-secondary level of education. The bursary is intended to help overcome the financial barriers to taking on new educational challenges. (More info: www.accd.net)

Disability in the Workplace Seminar

Workplace disability is an issue of substantial concern to employers, employees, unions, and public policy makers. This presentation will explore the results of Dr. Kelly Williams' field investigation to identify other factors that might impact reintegration and to develop a model that is more reflective of workplace realities. (Feb 9th in Calgary. More info: Melissa, 232-0759)

Navigating the Waters: Pre-employment Preparation Project

This Independent Living Resource Centre project offers opportunities for people with disabilities to develop employment skills, employment search strategies and/or obtain employment. (More info: Kelli, 263-6880)

Students with Disabilities in Post-secondary Institutions

A new publication is available from Alberta Human Rights and Citizenship Commission entitled Duty to Accommodate Students with Disabilities in Post Secondary Educational Institutions. This is a 29 page document regarding the definition of accommodation, the responsibilities of students and post-secondary institutions, examples of accommodations, and resources. (More info: www.albertahumanrights.ab.ca)

Bullying at school adapted from Exceptional Parent Volume 34 Issue 12

Children need a school environment that is safe and supportive for learning. But many families know all too well that children with disabilities can encounter teasing at school.

Teasing is often part of the school experience. It lies along a continuum that ranges from friendly bantering to bullying or harassment. There are distinctions between teasing and bullying.

Teasing involves pestering or making fun of someone. Bullying is if someone is intentionally cruel or overbearing toward another person who may be weaker physically or mentally. It is also the constant teasing that makes life miserable at school and involves severity, persistence, and pervasiveness of the behaviour.

In real life, teasing and bullying may overlap. A frequent scenario of unwanted teasing is when one student leads in "picking" on another child, and other children join in. If that happens, schools can send a message that students need to show respect each other and not make another's life miserable by teasing. The leader may not quit teasing, but many of the followers will because most children do not want to get in trouble.

The expectation is not that schools can prevent all teasing, but that the adults at school consistently send a message that they will not tolerate bullying. In schools where this occurs, parents notice diminished teasing and bullying.

Parents can take steps if they suspect that their child is a target of bullying, to help their child to develop strategies on how to avoid or confront bullying behaviour:

1. Listen to your child and observe any changes in behaviour. Realise that each child is an individual. What may not affect one child may extremely distress another.
2. Discuss the situation with your child.
3. Teach your child specific words to use in response to the teasing. For example, the child might say, "I don't like it when you call me names."
4. Look at ways your child can stay away from the children doing the teasing. That may include sitting in a different location in the lunchroom, participating in different activities on

the playground, or sitting in a different place on the bus.

5. Keep a record of what your child describes as happening at school. Include a) dates, b) who was involved, c) what was said, and d) the name of someone who might have seen or heard the incident.
6. Discuss with your child what the next step might be, such as your speaking to the teacher about what has happened. Be aware that your child may not want you to tell the teacher for fear of retaliation or being labeled a tattletale.
7. Inquire if your child's school has peer mediations. If so, have your child request mediation with the students involved.
8. If you speak to the teacher about the teasing or bullying and the issue

is ignored, send the school principal a letter containing a) the date on which you spoke to the teacher, b) your concerns, c) specific information about the incidents, and d) the adverse effects of the taunting on your child. Ask to meet to discuss the situation.

9. Inform the principal that you expect school staff to send the message to all children that teasing and bullying will not be tolerated.

10. If the principal does not intervene, send copies of the letter you sent to the principal to members of the school board requesting a written reply on the action the school will take.

If parents and school staff intervene appropriately, it is possible that teasing will not escalate into bullying.

Skin Care and Breakdown - Avoiding Pressure Sores

Christopher Reeve's untimely death reminds us of the need to be on the lookout for the ever-present danger of pressure sores. The actor died suddenly on October 10th, 2004. Reeve's demise began with a pressure sore, which became severely infected and the infection spread throughout his body. A day before he died, Reeve suffered a massive heart attack and fell into a coma.

A pressure sore is defined as any lesion caused by unrelieved pressure resulting in damage to the skin. The skin is the largest organ of the body and forms a protective barrier against bacteria, chemical and physical actions, as well as regulating temperature and providing sensory information.

Pressure sores occur when the skin is pressed between the bones of the skeleton and a hard surface which restricts the normal flow of blood, oxygen, and nutrients to the area. Subsequently the skin cells die, forming a pressure sore. Infection can easily spread to the rest of the body and, if left untreated, it can cause deeper injury to muscle and bone.

Prevention is the key to pressure sores.

This is best accomplished with braces that fit well, avoiding wrinkles in clothing, managing incontinence, and doing daily skin checks.

Change your position: Every 20 minutes lift your bottom off the chair and change the position of your legs. This allows the blood to flow normally for a few seconds (that's all it needs!). If it is too difficult to lift your bottom, then try a change of position; leaning forwards or to one side then the other. Take care when transferring from your wheelchair not to knock or drag the body.

Regular inspection of the skin: Ideally the whole body should be inspected night and morning for signs of any redness or changes in the skin. A long-handled mirror is very useful for inspecting the back and bottom.

Diet: A good balanced diet is essential for both the prevention and healing of pressure sores. An adequate intake of fluids helps to keep the skin supple and hydrated. Complex carbohydrates (bread, rice, pasta) will keep the muscles healthy. Iron-rich food such as spin-

ach, will help the blood carry the oxygen around the body to the cells. Vitamin C and zinc (a mineral) both help wound healing, as does an adequate supply of protein (found in meat, fish and dairy products).

Wear suitable clothing: Avoid clothes that are too tight or have hard seams, zips or buttons that might cause pressure. Good fitting shoes, with the feet put in properly, are essential.

Manage incontinence: Incontinence will cause the skin to become even more prone to damage as both urine and feces contain substances that break down the skin and cause it to become infected. Adhere to your bowel and bladder routine, and be sure to wear appropriately fitting diapers. Barrier creams can be useful but the most important protection is to clean up and change as soon as an 'accident' has happened.

Avoid burns: Because of poor circulation and poor nerve supply, the skin is not strong and will burn more easily than normal. Use sunscreen on all areas of the skin that will be exposed, and reapply frequently. Be sure to check the temperature of exposed surfaces with your hand before transferring to them. Use a protective towel or potholder on your lap if you will be carrying plates of hot food.

Wheelchairs and braces: Evaluate their fit on a regular basis to ensure there are no pressure points. A good rule of thumb is that any reddened area that does not disappear within 30 minutes after removal of the brace requires attention.

Preventing pressure sores takes a little effort, but it is very worthwhile; pressure sores take a long time to heal.

NVLD: Promoting Success and Independence

Children with nonverbal learning disabilities should be expected to perform all of the same tasks and chores as would be expected of any other child their age. In addition, they should be encouraged to develop recreational interests and participate in social and sports activities in the community.

Managing tasks and chores: The strategies used for children with ADD can be very helpful. For example, parents can facilitate the completion of the daily routine and chores by breaking the task into smaller components. Checklists can be used to help the child identify and complete each step of the task. Schedules and other organisational tools can help the child manage his/her school bag, notebooks, and homework assignments.

Increasing independence in the community: Children with NVLD may require explicit instruction about how to identify landmarks in their neighbourhood and make their way home, or how to manage interactions in public places such as stores and restaurants. Providing a written set of instructions and/or pre-rehearsed scripts can facilitate this.

Creating social opportunities: Social opportunities can be provided with other children with similar interests. The child should be encouraged to participate in activities that do not tax their organisational and

motor weaknesses. For example, a child with NVLD may not be successful in an activity such as basketball which requires motor coordination as well as understanding social cues and complex rules, but can be encouraged to join a ski club or swim team. Further, the people who interact with the child can help to build social and other skills. Any information provided about the child will be appreciated. One way to do this is to explain to others that the child is learning about social interactions, and that he or she will appreciate feedback if he appears confused, or if he misunderstands a joke and gets angry for no apparent reason.

School success: Children with NVLD can be mainstreamed in most courses at school, though they will likely require remedial help with arithmetic and higher order language functions, especially in later years. Most have difficulty with handwriting, and with traditional extracurricular activities such as physical education and art. Keyboarding can be used to circumvent handwriting weaknesses.

Social skills training: Social skills training is important both for the child's emotional health, as well as for training of concepts that are needed to understand higher-order reading and language tasks. The child's attention has to be drawn to the components of social interac-

tions described above. The parent or tutor can help the child by being very explicit about his/her own actions, and the intentions behind those actions. For example, the parent can explain why he is raising his voice or emphasizing one word versus another, why she is looking in one direction versus another, or why he is making close eye contact versus looking away. The child should be encouraged to create theories about what the conversational partner might be thinking or feeling. Finally, the child should be encouraged to ask for further clarification of social interactions when the meaning may not be clear.

Expanding reading comprehension: Reading weaknesses typically become apparent once reading demands exceed the grade four level. The tutor needs to assure that the child understands any spatial, time, or social concepts that may be included in the reading passage. Complex words or concepts will require additional explanation and/or review.

Clinical interventions: Children with NVLD can benefit from mental health services. To begin with, they should be encouraged to learn to label their own emotions, to learn about their learning style and interests and to learn how to explain their needs to others.

Adapted from EP Magazine, Aug 04

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SBHASA Funding Programs

Residents of Southern Alberta (South of Highway 11) with spina bifida and/or hydrocephalus, or individuals whose disability is/was treated through the Myelo Clinic at the Alberta Children's Hospital are eligible to apply for the SBHASA's funding programs.

Requirements

- The Applicant must be a member of the SBHASA for at least one (1) year prior to the request.
- The Applicant must have a minimum of five (5) volunteer hours with the association over the past two (2) years.
- A Funding Program Form must be completed and signed by the Applicant or Guardian. A description of the item and the receipt must be provided to the Association for our records.

1. Support Fund

The maximum allowable amount is \$1,200.00 per applicant per year (January to December).

- General needs - such as home improvements, daily living
- Medical needs - such as medical equipment, unusual health expenses, cecostomy tubes
- Items that improve the quality of life for individuals with spina bifida and/or hydrocephalus will be considered

3. Recreational Fund

The maximum allowable amount is \$300.00 per applicant per year (January to December). Only one funding request per applicant per year.

- Any program or activity that promotes participation, health, and/or well being.
- Modified recreational equipment, such as hand pedalled bicycles.
- Programs that are funded by SBHASA are not included.

2. Personal Health Fund

The maximum allowable amount is \$500.00 per applicant per year (January to December). Only one funding request per applicant per year.

- Items required for bowel and bladder care that are not covered by AADL, private insurance or CSN.
- Applicant's portion of AADL, private insurance or CSN for bowel and bladder supplies may be submitted.

4. Education Fund (NEW)

The maximum allowable amount is \$700.00 per applicant per year (January to December). Only one funding request per applicant per year.

- Any program costs at an accredited educational institution, including tuition, text books or tutoring fees.
- Educational accessories, such as electronic organisers, educational computer programs or teaching aids.

Approval Process

Applications will be reviewed by the SBHASA Executive Committee and notification of their decision will be made to the Applicant.

