

Newsletter

Fall 2007



**Spina Bifida and Hydrocephalus
Association of Southern Alberta**
PO Box 6837 Station D
Calgary, Alberta T2P 2E9
Tel: (403) 263-1109
www.sbhasa.ca / info@sbhasa.ca

2007 fundraising casino successful

The SBHASA held our fundraising casino on September 10-11, 2007. We'll find out how much money we raised in October. This fundraising initiative allows us to continue supporting our members with spina bifida and hydrocephalus through the SBHASA funding programs.

A huge thank you goes out to our members and their families who were kind enough to put in their volunteer hours at this year's casino:

Roger Smith
Michelle Hamill
Denise Helwerda
Elizabeth Schofield
Elizabeth Costa
Richard Brekke
Jonathon Brekke
Roger Jensen
Daniela Liptak
Irene Shiu
Kathy Hawryluk
Gerda MacGregor
Kevin MacGregor
Aileen Carney-Brown
Maung Tun

Blair Desjardine
Jenny Aikenhead
Ashley Roach
Alma Bourne
Delphine Roach
Sharon Simon
Stephen Gratton
Kelly Webber
Teresa Webber
Whitney Pohl
Debbie Richter
Brian MacGregor
Cheryl MacGregor
Derrick Czayka
Joe Dzurilla

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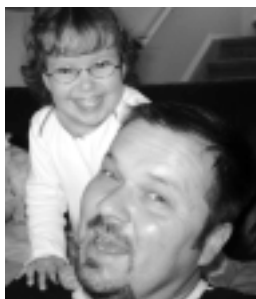
Extra thanks to those who served as last minute back-ups: Roger Jensen, Elizabeth Schofield, Debbie Richter, Jenny Aikenhead and Daniela Liptak. Also to Jonathan Bateman who recruited a couple of volunteers even though he wasn't able to volunteer himself. That is the true spirit of volunteer work.

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.

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President's Message - Joe Dzurilla

I guess it's about time that I introduce myself to our membership, and those people whose lives our Board of Directors tries to improve. My name is Joe Dzurilla, and I am married to Zuzana and father of Alexandra (age 5). I first got involved with the association when Alexandra was born, so I could find out as much about Spina Bifida and Hydrocephalus as possible. I have since received invaluable advice and suggestions on how to deal with the issues that my daughter faces and will face. I thank those who have supported me and my family during difficult times.



You probably have seen the same names on the list of Board of Directors over the past 5 or so years. I want to thank the members of our Board for their hard work and diligence in keeping the Association a viable entity. I had mentioned at our Annual General Meeting that we are a "tired" Board, and we are in need of some new members to volunteer their time to serve our membership. I usually am an optimistic person, however, in this case I feel it's important to stress our situation.

If you haven't met me, it means that you haven't volunteered at the casino for the last three years! For those that I have met while doing a casino event, I want to say thank you and that honestly it's been a pleasure to meet you. I have heard plenty of personal stories (both success and the challenges) of our membership and gotten to know who our Board serves.

Our next casino will be held in early 2009. I would like to see less of the McGregor clan there, as they provided 6 volunteers as they do every casino event, and see more new faces.

On a different note, as we go on to serve you over the next year, I ask that those sending in funding requests fill out the forms correctly, organize your receipts with a staple or paper clip, and calculate the gst that is included in your request. This makes it much easier of the person who volunteers their time to send you your funds!

Finally, I would like to see some new faces at our board meetings. We look forward to any new ideas or suggestions that may arise. As we aim to build a stronger Association, I think each of us has something to offer. A few hours of your time that you will find is fulfilling as you serve your community.

AccessAbility Scholarship

MuchMoreMusic is accepting applications for its AccessAbility Scholarship, a \$5,000 scholarship created in partnership with the National Education Association of Disabled Students (NEADS) to be awarded to the individual who best demonstrates skill, talent, excellence and enthusiasm in pursuing a future in the broadcast industry.

Deadline to apply is November 1, 2007. For info, visit www.muchmoremusic.com/scholarship.

United Way Donations

You can donate to the SBHASA through the United Way campaign. Use our registration # 11915 9481 RR0001, and we will receive 100% of the proceeds designated to us.

Federal Excise Gasoline Tax Refund Program

You may be eligible for this program if you are an individual who has a permanent mobility impairment and cannot safely use public transportation, as certified by a qualified medical practitioner. The program allows you to claim a refund of part of the excise tax on gasoline at the rate of \$0.015 per kilometer. To find out more or get a form go to:

www.cra-arc.gc.ca/E/pbg/ef/xe8/xe8-00b.pdf



2008 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, 2008.

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.

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 \$ _____

Please Print:

Name(s) _____
Last First

Last First

Address _____

City _____ Postal Code _____

Telephone _____

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.)

_____ Other _____

I can volunteer to help the association and other families:

_____ Executive

_____ Committees

_____ Phoning

_____ Fundraising

Teaching a child with Spina Bifida and Hydrocephalus

Although most children with SBH are within the normal range of intelligence, the majority experience specific learning difficulties. These problems are primarily related to the neurological partners of spina bifida: hydrocephalus and the Arnold Chiari malformation.

In the past students with SBH were sometimes labelled incorrectly as lazy, careless or clumsy. You can help your child to succeed at school by sharing the following information with his/her teacher.

In The Classroom

- John does not remember today what he appeared to know last week.
- Susie talks a lot but is often off the point. She does not listen effectively and the other students find this irritating.
- Toby seems interested and starts tasks willingly, but rarely completes anything. His writing is awful.
- Peter works well when the teacher or aide sits beside him but he gets distracted and produces little if left to work on his own.
- Melissa forgets due dates for work requirements.
- Sean finds it difficult to grasp fundamental mathematical and spatial concepts.
- George can learn effectively but this often takes longer than his peers.

The above statements often apply to students with SBH. Although they may sound like difficulties that can affect any student every once in a while, it must be realised that for SBH students these problems are pathological in origin and need to be addressed accordingly.

What follows is a short description of how typical learning problems manifest and some recommended strategies for educators when confronted with them. The teacher's knowledge and experience of their students will be the best guide to the distinctive pattern of cognitive strengths and weaknesses exhibited by individual students.

Attention - Most SBH students appear interested and motivated to learn. However they are easily distracted and find it difficult to sustain attention until the completion

of work. Some have difficulty identifying the most salient aspect of a task and focusing their attention. Instead they tend to get distracted to less relevant aspects.

Students with attention problems usually function best when:

- the work environment is quiet, well organised and clearly structured;
- a single activity is set and competing distractions are minimised;
- high demand working periods are brief and interspersed with more relaxing activities;
- instructions are clear and step by step and repeated when required;
- adult assistance is available to redirect the student after lapses in concentration.

Language - Students with SBH are often described as sociable and talkative with good vocabulary skills. However, they may have difficulty monitoring what they say for logic, relevance or appropriateness. This poor comprehension may be difficult to identify when associated with articulate presentation. Some 'over talk', perhaps to compensate for their limited mobility or to conceal their inability to do what is asked, may be evident. Teachers can help by:

- encouraging the student to use language for communication of meaning rather than only to manipulate others or to conceal areas of difficulties;
- insisting that the student maintains a shared topic of conversation and redirecting them if they wander;
- routinely checking the student's understanding of the language they are using (for example, by asking the

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student to paraphrase what is said to them, particularly instructions).

Memory and Learning - Immediate memory for auditory/verbal information may be intact, i.e. the student has an age appropriate capacity to remember instructions or explanations immediately after they are given. However, there is a rapid loss of information over time and difficulty in retrieving the appropriate bit of information from long term memory when it is needed. Visual memory is weak and concepts grasped last week are later lost. Students with SBH can learn effectively however often take longer to learn and struggle with abstract concepts, for example, mathematics. During bad periods they may appear lazy or 'inert' and simply cannot function at the level they are capable of.

Students with memory learning deficit are helped by:

- reducing the amount of information presented at one time and allowing extra opportunity for rehearsal;
- emphasising key points in a logical sequence - information is remembered most effectively when it is processed in an organised and logical way. Extraneous information should be minimised;
- reinforcing conceptual learning through practical activities related to the student's interests and life experience.

Visuo-Motor Integration Skills - Most students with SBH have difficulty with tasks requiring eye-hand coordination and motor planning skills. They may have difficulty with accurately interpreting what they see in terms of shape, size, space, distance and then correctly matching their movements (gross or fine). Some students may experience confusion differentiating between left and right. Complaints about slow and untidy handwriting are common and written tasks are often not fully completed.

Assistance can be given by:

- allowing extra time for written work or assignments;
- providing alternatives, for example using an audio tape for creating writing activities;

- encouraging early and frequent use of a word processor for the presentation of written work;
- providing activities which allow the above skills to be practised.

Planning and Organisational Skills - Most students with SBH find it hard to organise themselves, plan ahead and think flexibly. In addition, some may experience difficulty in understanding the passage of time or understand when matters are urgent. They may be unable to generate strategies for solving problems or to alter their approach if the first attempt is unsuccessful. They seem lost when confronted by a novel or multi-staged task and their work output falls off when they are expected to work independently.

Teachers can help by:

- breaking down complex tasks (eg. assignments, projects) into smaller steps, helping the student generate a plan of approach before they commence, reviewing progress after each component step has been completed and, in brief, providing signposts to guide the student's progress;
- encouraging organised work habits, eg. set homework times, the use of a diary, focusing on time management, use of written or pictorial check lists, use of colour coding to assist planning;
- encouraging the student to check and proofread their work.

The levels of educational achievement of students with SBH are in a wide range, from completion of university and vocational training programs to non-completion of secondary schooling. Whatever the potential of individual students, through awareness of the specific learning difficulties listed above and consistent strategies to intervene where necessary, educators will assist them reach their full potential.

Adapted from Educating the Child with Spina Bifida, ASBAH

Skin Care - pay attention to prevention

When you get new braces

Many brace wearers face the risk of pressure sores that can be caused by staying in one position long enough to put forceful pressure on a body part. You're more at risk if you lack sensation and can't feel discomfort that would cause others to shift their bodies without thinking about it.

To prevent skin problems, remove a new brace for a skin check every 30 minutes on the first day. If there are no red spots left on the skin after 20 minutes, continue increasing the time that you wear the brace until eventually you wear it all day. If you continue to have redness, see your orthotist for an adjustment. Remember, it may feel like a nuisance to check for pressure spots, but getting a pressure sore would be an even bigger nuisance.

Anything exerting pressure on a body part with limited sensation can cause a problem. Seams on your socks? Try wearing them inside out. Thick seams or grommets on your jeans? Avoid these when shopping for clothes. Tight underwear that binds? Loosen it or buy a larger size. Skin that has broken down and healed over is never as strong as skin that has never experienced a breakdown.

When you start using a wheelchair

Make sure your wheelchair has a good pressure relief cushion that is appropriate for your size, weight, and mobility. Work with a physical therapist or wheelchair vendor who is knowledgeable about seating issues to get the right cushion. Then develop the habit of shifting to prevent pressure sores.

Doing weight lifts or shifts every 30 minutes in your wheelchair is important. Your skin can't take prolonged pressure or excessive forces. The tiny blood vessels that supply the skin with nutrients and oxygen can be squeezed and cause the skin to be starved of blood and the tissue to potentially die, causing a pressure ulcer.

Aim for lifting your rear off the seat for 15-30 seconds every 30 minutes. Set an alarm on your watch if you need a reminder to shift. Talk with your physiotherapist about effective ways to shift to prevent pressure sores and about other ways to relieve pressure. For example, armrests on your wheelchair can assist with shifts. A higher back on your chair can take some of the pressure off your rear. Finally, lifting your body rather than sliding it when transferring can protect your skin from a kind of pressure called shearing.

Healing a pressure sore

Your health care provider can recommend treatment for a pressure sore, including how to clean and dress the sore. Keep pressure off that area until it heals. Watch for any changes or signs of infection and report them immediately.

Because good nutrition helps to heal a sore and because healthy skin is less likely to break down, develop the habit of eating a well-balanced, high-protein diet and take a daily high-potency vitamin and mineral supplement as well. Supplemental vitamin C and zinc may help with healing. Above all, don't smoke; smoking decreases oxygen to the skin and prevents healing.

If you're overweight, extra pounds can create extra pressure. Alternately, if you're underweight, the lack of muscle and body mass makes skin less tolerant of stress. Bottom line, prevention of pressure sores is another good reason to maintain a *healthy* weight.

Keep your skin clean and dry: skin that is frequently moist from urine, sweat, or stool is more likely to break down. Dry skin well after bathing, but don't rub hard with a towel as rubbing can damage the skin.

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

2. 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.

3. Education Fund*

The maximum allowable amount is **\$500.00** 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. Computer (hardware) purchases held to a maximum of \$500.00 of Education Fund only (no use of Support Fund).

Applications will be reviewed by the SBHASA Executive Committee at the subsequent board meeting. Total funding disbursements cannot exceed the yearly budget amount. If requests surpass the budgeted amount, the Executive Committee shall at that time review the Funding Program and implement necessary changes.



SBHASA '07 Funding Program Application

This is an application for the Spina Bifida and Hydrocephalus Association of Southern Alberta (SBHASA) funding programs. Please provide all of the information requested, and attach your official receipts. Falsification of any information will result in automatic rejection of the application.

Payable to: _____

Mailing Address: _____

City: _____ Postal Code: _____

Telephone: _____ Email: _____

Name of Member with SB/H: _____

Date of Birth: _____

Volunteer Time (list events, committees and hours): _____

I am applying for:	ITEM(S)	COST	GST	TOTAL
Support / PH (max \$1200)	_____	\$ _____	+ _____	= \$ _____
Recreation (max \$300)	_____	\$ _____	+ _____	= \$ _____
Education (max \$500)	_____	\$ _____	+ _____	= \$ _____
Total cost:	_____	Amount applied for: _____		

REQUESTS WILL NOT BE PROCESSED WITHOUT AN OFFICIAL RECEIPT

All requests for items purchased in 2007 must be submitted by January 31st, 2008.

I hereby certify that the above information given is true, correct and complete to the best of my knowledge.

Signature: _____ Date: _____

Send completed forms to: Spina Bifida & Hydrocephalus Association of Southern Alberta
P.O. Box 6837 Station "D" Calgary, Alberta T2P 2E9