

Newsletter

Winter 2008



**Spina Bifida and Hydrocephalus
Association of Southern Alberta**
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Camp Horizon for teens

The SBHASA is planning to run a weekend camp in September at Camp Horizon.

The camp will be for teens with spina bifida. Campers will work on independence skills, becoming more active in the community, and discussing other transition topics including driving, relationships, and scholarship opportunities.

There will also be plenty of fun activities, such as rock climbing, camp fires and more.

Please contact Lyndsey Clark through the SBHASA if you are interested in this camp so that we have an idea of how many people will attend. All campers must be SBHASA members.

Watch for more information and registration details in the next SBHASA newsletter.

To find out more about Camp Horizon, or take a virtual tour of their facilities online, visit:

<http://www.easterseals.ab.ca/camp/>



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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.

SBHASA

New faces at ACH myelomeningocele clinic

Linda Gill, Clinical Resource Nurse

Hello - I'm Linda Gill, the clinical resource nurse replacing Stephanie Birkett in the Myelomeningocele Clinic at the Alberta Children's Hospital.

I have worked at the ACH since 1997 as a Nurse Clinician. Prior to that, I worked in Ontario for many years on a Med-Surg unit as a staff nurse.

I am very committed to my family, which includes 2 granddaughters. We enjoy hiking, biking skiing, skating, curling and like to travel.

I look forward to meeting all of the children and their families at ACH, as well as other members of SBHASA.

Please feel free to call me with any questions or concerns, or drop by the Neuroscience Department at ACH.

Lyndsey Clark, Occupational Therapist

For those of you who have not met me, I have been the occupational therapist on the myelo clinic at ACH for just over a year.

My previous experience involved working in the adult sector with patients with neurological disorders, particularly stroke, traumatic brain injury and spinal cord injury. My experience working with adults has led to a particular interest in working with teens, assisting them with becoming more independent as they move towards becoming an adult.

Starting in February, I am also trialing working in a transition position for teens involved in Neuroscience Clinics at ACH. I look forward to meeting everyone. If you have any questions regarding OT or your child needs to be involved with OT services, please don't hesitate to contact me.

Intermittent Catheterization Study

Some children with Spina Bifida who use intermittent catheterization to empty their bladder may get bladder infections. We want to know if a new catheter, called the SpeediCath, helps reduce the risk of developing infections.

We are looking for families and children to take part in a study to see if the SpeediCath catheter helps reduce bladder infections compared to usual catheterization with clean reused catheters. Each family will use the SpeediCath for 6 months and their usual catheterization method for 6 months. There is no charge for the SpeediCath.

Taking Part: If you are interested in learning more about the study, please call the research nurse, Megan Allison:

Telephone: (403) 244-4391

Email: megan.allison@calgaryhealthregion.ca

You may also ask the nurses and physicians at the Myelomeningocele Clinic about the study.

This study has ethical approval from the University of Calgary Office of Medical Bioethics. Taking part will not affect your health care in any way, and all information about you will remain confidential.

Researchers: William Hyndman, MD, Calgary
Darcie Kiddoo, MD, Edmonton
Katherine Moore, PhD, Edmonton



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.)

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

S B H A S A

Annual General Meeting

The SBHASA's AGM will be held at the Alberta Children's Hospital (room to be determined) at 7:00pm on Monday, May 12, 2008.

All Executive Committee positions are open:

President
1st Vice-President
2nd Vice President
Secretary
Treasurer
Member at Large

Please send nominations for any positions to info@sbhasa.ca or phone Gerda at (403) 247-1332 by May 1, 2008 to submit nominee's names.

A farewell celebration will be held for Jenny Aikenhead directly following the AGM.

RSVP your attendance to the AGM and farewell by email info@sbhasa.ca or leave a message on the SBHASA's voice mail at (403) 263-1109.

Sleep Study

A study is being conducted regarding breathing problems during sleep in children with myelomeningocele. For information, contact the project coordinator, Mitch:

(403) 955-3189
(403) 955-2239

Linda Gill in the Myelomeningocele clinic can provide you with an information sheet on the study.

New website boon to disabled

There's a new online gathering place where revealing that you use a wheelchair or can't hear is no big deal, because the person you're chatting with probably lives a similar experience.

Disaboom.com - so named because the creator wanted to "blow the doors off" stereotypes - is a website for the disabled community that combines lifestyle and medical information, discussion boards, social networking, a career centre and a dating site. It lays claim to being the first for-profit online destination for people with disabilities, which translates to a slick, sophisticated space with plenty of resources.

Conversations range from a mother worried that her two-year-old isn't yet walking with his prosthesis to advice on sex after a spinal cord injury and the fine art of "signaoke," or karaoke for the hearing-impaired.

There are also lively discussions about all sorts of topics that have nothing to do with disability. "It's a never-ending search for a good website where people with disabilities can go and get together," says Darren Forsyth, 33, a paraplegic who lives in Regina. "When I found Disaboom, it was an automatic connection."

The site has attracted more than 350,000 unique viewers from 178 countries since its October launch. "It's almost like a support group, but it's the entire world at your fingertips," says founder and chief medical officer Dr. Glen House.

A skiing accident in college left him with no movement below the chest and limited dexterity in his hands. House is now medical director of the Center for Neuro and Trauma Rehabilitation in Colorado Springs.

House sustained a spinal cord injury in the pre-Internet dark ages of 1990, so the only resource available to him at the time was a few people at a support group meeting. As a doctor, he realized he was having the same in-depth bedside chats with all of his patients, offering a mix of medical knowledge and his own experience. The Internet provided a global vehicle for people to share expertise about living with disabilities, and so Disaboom was born.

On the web: www.disaboom.com

by Shannon Proudfoot, CanWest News Service

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The Government of Canada helps people with disabilities to fully participate in the workplace

OTTAWA, ONTARIO, November 22, 2007 — The Government of Canada is helping Canadians with disabilities develop the skills they need to find and keep good quality jobs. Today, the Honourable Monte Solberg, Minister of Human Resources and Social Development announced support for Canadians with disabilities to help them develop skills and secure meaningful, long-term employment.

"Our Government is working with the provinces and territories to support programs and services to help Canadians with disabilities secure better jobs and build better lives," said Minister Solberg. "By providing persons with disabilities training that employers are looking for and the support they need to fully participate in the workplace, everyone wins."

Through the Labour Market Agreements for Persons with Disabilities, the federal government works with provinces and territories to put in place programs to assist people with disabilities to overcome barriers and become active in the labour force. These agreements, which have now been extended until March 31, 2009, support a broad range of provincially delivered programs and services, including: job coaching and mentoring; pre-employment training and skills upgrading; post-secondary education; and a variety of workplace supports.

Today's investment of \$223 million also reflects the goals of Advantage Canada, the Government's economic plan, to create the best-educated, most-skilled, and most flexible workforce in the world and identifies people with disabilities as one of the groups facing unique challenges to labour market participation.

Budget 2007 committed \$3 billion over six years, \$500 million per year, in a comprehensive new labour market program to improve skill levels. The goal of these new investments is to help deal with the demand for workers by maximizing the contribution of the existing labour force and increasing the participation of those groups currently under-represented in the labour market, including persons with disabilities.

Non-Verbal Learning Disabilities - information on the web

Nonverbal Learning Disorders
<http://www.idonline.org/article/6114>

NVLD: How To Recognize It And Minimize Its Effects
http://www.schoolbehavior.com/conditions_nvld_foss.htm

Non-Verbal Learning Disabilities: An Emerging Profile
<http://www.nldline.com/frankenb.htm>

Frequently Asked Questions- What is NVLD?
http://www.the-callahans.com/susetef/faq_nvld.htm

NVLD: A Primer on a Puzzling Population
<http://www.nclد.org/content/view/1124/398/>

Understanding Nonverbal Learning Disability (NVLD)
<http://www.nldontheweb.org/heller.htm>

Nonverbal Learning Disorder - Brief overview
http://www.schoolbehavior.com/conditions_nvld.htm

Nonverbal Learning Disabilities
<http://www.schwablearning.org/articles.aspx?r=967>

Descriptive Profile of Children with NVLD
<http://www.nldline.com/palombo.htm>

The Misunderstood Child: The Child With a NVLD
http://www.nldontheweb.org/little_1.htm

S B H A S A

Canadian Transportation Agency decides in favour of one-person-one-fare policy

OTTAWA - January 10, 2008 - The Canadian Transportation Agency has ordered Air Canada, Air Canada Jazz and WestJet to adopt a one-person-one-fare policy for persons with severe disabilities who travel within Canada by air. The airlines have one year to implement the policy.

The tribunal's Decision means that for domestic services, Air Canada, Air Canada Jazz and WestJet may not charge more than one fare for persons with disabilities who

- are accompanied by an attendant for their personal care or safety in flight, as required by the carriers' domestic tariffs, or
- require additional seating for themselves, including those determined to be functionally disabled by obesity for purposes of air travel.

The Decision does NOT apply to:

- persons with disabilities or others who prefer to travel with a companion for personal reasons;
- persons with disabilities who require a personal care attendant at destination, but not in-flight; and
- persons who are obese but not disabled as a result of their obesity.

The Decision is based on longstanding principles of equal access to transportation services for persons with disabilities, regardless of the nature of the disability, and the Agency's legislative mandate to remove "undue obstacles" to their mobility. The Decision respects related decisions of the Supreme Court of Canada and Federal Court of Appeal.

The airlines are expected to develop a screening process to assess eligibility under the one-person-one-fare policy. For persons who travel with an attendant as required by the carriers' domestic tariffs, the Decision notes that carriers already perform assessments and have screening mechanisms to determine fitness and conditions for travel. Their screening mechanisms could be adapted to include functional assessments, and related screening expertise is available to them. For persons disa-

bled by obesity, the Agency cites the practical experience of Southwest Airlines, which screens for entitlement to an additional seat by determining whether a person can lower the seat's armrests.

The airlines failed to demonstrate to the Agency that implementation of a one-person-one-fare policy will impose undue hardship on them. The Agency estimates that the cost of implementing the one-person-one-fare policy represents 0.09 per cent of Air Canada's annual passenger revenues of \$8.2 billion and 0.16 per cent of WestJet's equivalent revenues of \$1.4 billion.

In a separate statement released today, the Agency offered to facilitate a collaborative process for implementation of the one-person-one-fare Decision. "It would be desirable to have a common screening approach to determine eligibility to benefit under the one-person-one-fare policy," said Geoffrey Hare, Chairman and CEO of the Agency. "A co-operative approach would be potentially beneficial to Air Canada, Air Canada Jazz, WestJet and the Gander International Airport Authority as well as other Canadian air carriers and airport authorities that may consider voluntary implementation of the one-person-one-fare policy."

The Canadian Transportation Agency is an independent tribunal which operates like a court to render decisions on a case-by-case basis. The Agency's jurisdiction with respect to persons with disabilities, stated in Part V of the Canada Transportation Act, is to ensure that persons with disabilities have proper access to effective transportation service. The Agency makes decisions and orders to eliminate undue obstacles to the mobility of persons with disabilities in the federal transportation network.

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Registered Disability Savings Plan

Q.1 What is the Registered Disability Savings Plan (RDSP)?

A.1 The Registered Disability Savings Plan is a new plan that will allow funds to be invested tax-free until withdrawal. It is intended to help parents and others to save for the long-term financial security of a child with a disability. The plan structure is similar to a Registered Education Savings Plan.

Contributions to an RDSP will be eligible for the new Canada Disability Savings Grant. There is also a new Canada Disability Savings Bond for individuals with lower family net incomes.

Q.2 Who will be eligible for the Registered Disability Savings Plan (RDSP)?

A.2 Any person who is:

* Eligible for the Disability Tax Credit and is a Canadian resident; or

* A parent or legal representative of a person who is resident in Canada and is eligible for the Disability Tax Credit.

Q.3 Who can contribute to a RDSP and how much?

A.3 Anyone can contribute to an RDSP; however, contributions are limited to a lifetime maximum of \$200,000 in respect of the child, with no annual limit. Contributions will be permitted until the end of the year in which the child attains 59 years of age.

Q.4 When will the Registered Disability Savings Plan (RDSP) come into effect?

A.4 As soon as possible in 2008. Check our Web site often - all new forms, policies and guidelines will be posted on the CRA's Web site as they become available.

Q.5 What are the Canada Disability Savings Grant and the Canada Disability Savings Bond?

A.5 These are two programs designed to augment funds in the RDSP. The government will contribute, in the form of Canada Disability Savings Grants, funds equivalent to 100% to 300% of RDSP contributions, up to a maximum of \$3,500 depending on the net income of the beneficiary's family. The government will also contribute up to \$1,000 annually in Canada Disability Savings Bonds depending on the net income of the beneficiary's family.

Q.6 Where can I get more information about the Registered Disability Savings Plan (RDSP)?

A.6 More information about this plan will be available shortly. Please check the CRA's Web site (<http://www.cra-arc.gc.ca>) regularly for updates.



SBHASA '08 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 (max \$1200)	_____	\$ _____	+ _____	= \$ _____
Recreation (max \$300)	_____	\$ _____	+ _____	= \$ _____
Personal Health (max \$500)	_____	\$ _____	+ _____	= \$ _____
Education (max \$700)	_____	\$ _____	+ _____	= \$ _____
Total cost:	_____	Amount applied for: _____		

REQUESTS WILL NOT BE PROCESSED WITHOUT AN OFFICIAL RECEIPT

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