

# Newsletter

Fall 2006



**Spina Bifida and Hydrocephalus  
Association of Southern Alberta**  
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## ***Take Action 2006 Conference Report***

More than 40 people from SBHASA attended the Take Action 2006 National Conference on Spina Bifida and Hydrocephalus held in Edmonton in September, and by all accounts it was a raging success.

Those in attendance were lucky enough to hear a keynote address by Alvin Law, a speaker like no other. Born without arms, Alvin has always lived by the motto, "There's no such word as can't!" To hear him talk about the incredible power of humanity and the difference each person can make in the world was truly uplifting.

Sessions at the conference included Cecostomies, Depression and Anxiety, Non-Verbal Learning Disorders, Neurosurgery, Skin Breakdown and Wound Care, Keeping a Healthy Bladder, Fitness and Adapted Sports, Orthopedic Surgery, Home Accessibility, Advocacy and Inclusion, Nutrition, Navigating the School System, and Sexuality, Dating and Relationships. Something for everyone!

Members with spina bifida who did not attend conference and would like a personal inspection mirror and / or book on how to prevent pressure sores (written by Jenny Aikenhead, Stephanie Birkett, illustrated by Melanie Aikenhead), please contact the SBHASA. Limited supplies are available, and will be distributed on a first come first served basis. Please note, the mirrors are for members 10+ please.

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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.

# S B H A S A

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## President's Message

I was thrilled to be a part of the Take Action 2006 conference on Spina Bifida and Hydrocephalus in Edmonton this fall. As expected, it was a tremendously positive experience for everyone who attended.

Advances in health care and technology mean that people with Spina Bifida and Hydrocephalus are living longer and fuller lives than ever before. But what challenges will they face as they age? This conference gave us all the opportunity to come together with others in the SB&H communities to discuss these challenges, to make new friends, to educate ourselves about new technologies and medical practices, and most importantly to get involved in some way – to take action with our lives.

I enjoyed my weekend in Edmonton – I'm sure I will look back on Take Action 2006 as a time of shared experience and learning opportunities that made a positive impact on me and my family. I hope each and every other SBHASA member has the opportunity to experience something of this nature at some point in their lives.

Douglas O'Muir

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## Equipment available to members

The SBHASA has purchased a number of items for members to use for assessment and short term use.

- 1 - 8 foot portable folding ramp
- 2 - 10 foot portable folding ramps
- 2 adjustable transfer benches for bath tubs
- 1 bath bench (half-in half-out of tub)
- 1 over the bed table
- 1 Rabbit mobile stander (pediatric size)
- 1 outdoor crosscountry wheelchair (14" seat)
- 1 quikie bike (bolts on to front of wheelchair)
- 1 small tricycle

All items are for **short term use only**, and can be borrowed for special occasions (ie holidays) or for use in your home. Please contact us at (403) 263-1109 or sbhasa@telus.net if you are interested in borrowing something.

## Membership Renewals

Please remember that SBHASA memberships run from January 1st to December 31st and need to be renewed every year in order to keep your membership up to date.

You can download the membership form from our website ([www.sbhasa.ca](http://www.sbhasa.ca)) or look for it in our next newsletter. The fee is still only \$10, a great deal considering all that membership entitles you to:

~ Regular newsletters from both SBHASA and SBHAC, to keep you up to date on all things sb/h

~ Access to SBHASA funding programs, up to \$2700 per member with sb/h per year

~ Eligibility for SBHASA Bursary, \$1500 per year to further your post-secondary education

~ Social and recreational opportunities with other sb/h families (ie conference, sledge hockey)

~ Chance to join the Board of Directors and make a difference

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## United Way Donations

Did you know that you can donate to the SBHASA through the United Way?

Simply ask for an "alternate charity form" and give them our name, address, and registration number (11915 9481 RR0001).

You will still donate in the same manner and get your charitable receipt from United Way, but can help out your local association at the same time.

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## Sledge Hockey is back



The SBHASA sponsored sledge hockey team is back in action, and there have been some changes made to the program.

This year there are 2 teams playing at the Stew Hendry Arena on Saturday nights - the Calgary Scorpions for athletes over 15 years of age, and the new Calgary Stingers made up of players below the age of 15.

The teams practice Saturday nights from 6:15pm to 8:15pm. There is also a game scheduled against Edmonton for November 4th, so head on down to cheer the Scorpions on and to see sledge hockey in action.

For more information, please visit their new website:

[www.calgarysledgehockey.ca](http://www.calgarysledgehockey.ca)

## New exercise video

"Teens on the Move" is an exciting new exercise video for teens with spina bifida produced through a collaborative effort by National Center on Physical Activity and Disability (US), the Rehabilitation Institute of Chicago (RIC), and the Spina Bifida Association of America (SBAA).

This complete exercise program features teens with spina bifida, and includes the following sections:

- 18 minutes of aerobic exercise
- 16 minutes of flexibility
- 26 minutes of strength training, including balance and core exercises
- Warm-up and cool-down exercises
- Closed captioning for individuals with hearing impairments

Find more information including how to order your copy at:

<http://www.ncpad.org/exercise/>

Don't forget to visit us on the web:

[www.sbhasa.ca](http://www.sbhasa.ca)

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## Cecostomy update

Effective May 1, 2006, the cost of the cecostomy tube will increase from \$235.00 to \$265.00 due to increased manufacturing costs. If you have any questions, please contact the ACH surgical clinic.

Remember, up to date members who have fulfilled their volunteer hours can apply to have their tube replacement covered in our Personal Health Fund.

## Wheelchair Curling

There has been continued interest in the wheelchair curling program in Calgary, which is organized in large part by Ernie Comerford. There are well over 20 sessions taking place this year on Saturdays at the Ogden Curling Club. The registration fee is \$50 for the year, but newcomers are welcome to a free trial period of a couple of weeks to see how they like it.

Anyone who is interested should contact Ernie at 236-3239 or [enjcomerford@shaw.ca](mailto:enjcomerford@shaw.ca).



# S B H A S A

## **Latex Allergies**, *exerpted from Sansun Highlights*

During the 90s, a strange and troubling new epidemic took place on a global scale: allergic reactions to latex or rubber products. Not only has this epidemic ruined careers, it has been responsible for a number of deaths.

To understand this epidemic, it is important to know how rubber is made. First of all, natural rubber latex is not synthesized in a laboratory - it is a completely natural product obtained from the Brazilian rubber tree, *Hevea brasiliensis*.

Latex is harvested much like maple syrup, from slits made in the tree's bark. The milky sap is pooled, treated with preservatives, then centrifuged to concentrate the rubber solids. Various chemicals are then added and the latex emulsion can be used to make products ranging from tires to rubber gloves.

The puzzling thing about latex allergy is that it is a relatively new disease; it wasn't a problem until the late 1980s. Since then it has burgeoned into a major health problem. The most compelling clue to the cause of this phenomenon was the adoption of "universal precautions" in 1987.

This policy mandated use of latex gloves to prevent transmission of bloodborne infections such as AIDS and hepatitis. As a result, the use of latex gloves skyrocketed; nearly nine billion gloves sold in the U.S. annually. Two years after universal precautions were adopted, however, the *US Food and Drug Administration* was besieged with reports of serious reactions to latex.

It also became clear that certain groups - nurses, doctors, surgeons, dentists, rubber industry workers, and patients who had undergone multiple operations -- were at especially high risk of latex allergies. The common denominator appeared to be repeated exposure to rubber products.

We now believe the cumulative exposure reached a critical mass for susceptible individuals to become

sensitized to latex proteins. Nearly 10 percent of healthcare workers were allergic to latex by 1997, and certain groups such as children with spina bifida are at even higher risk. Over half of these children will develop latex allergies, so it is recommended they avoid latex exposure from birth.

Reactions to latex can take a variety of forms. There are three types of skin reaction:

- irritant ("dish-pan hands"),
- delayed hypersensitivity (like poison oak, usually caused by chemical additives), and
- urticaria or hives.

Other reactions can mimic hay fever or asthma. The most serious are systemic reactions: angioedema (swelling of the lips, tongue, or throat) and anaphylactic shock. There is one other unusual manifestation: food allergies. Individuals with latex allergies are more likely to react to certain foods, especially bananas, avocados, chestnuts and kiwi fruits.

It is important to remember three key facts:

- 1) the severity of a previous reaction does not reliably predict the severity of a future reaction,
- 2) even casual contact with latex can cause severe reactions in highly-sensitive individuals, and
- 3) latex allergy can be mistaken for other allergies.

The good news is that with proper recognition, diagnosis, and management, most latex allergy sufferers can avoid the complications of this healthcare epidemic.

For more information visit:

**[www.latexallergyresources.org](http://www.latexallergyresources.org)**

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## Fundraising for the SBHASA in 2006

Thank you to everyone who volunteered their time at our casino this summer. The bulk of our funds is raised through the casinos, and we would not be able to provide our funding programs without our terrific fundraising volunteers:

Jo-Anne Laberge	Brian McGregor	Roger Jensen
Denise Helwerda	Marion Leslie	Jonathon Brekke
Colin Laberge	W. Tarnar	Bart Gross
Elizabeth Schofield	Freka Skinner	Jean Dzurilla
Aileen Carney-Brown	Alma Barne	Sue Peloski
Elizabeth Costa	Delphine Roach	Alice Laine
Michelle Laberge	Ashley Roach	Daniela Liptak
Walter Batawin	Kathy Hawryluk	Sharon Simon
Gerda McGregor	Dwayne Hawryluk	Steve Simon
Kevin McGregor	Richard Brekke	Irene Shiu
Cheryle McGregor	Michelle Hamill	



Steven Greene of Calgary was one of several members who sold bendable daisies during SB/H Awareness month in June.

**Thank you volunteers!!**

## **SBHASA Board Meetings**

The SBHASA Executive Committee meets on the second Tuesday of the month on alternate months. Meetings will now be taking place at the new Alberta Children's Hospital in the Musculoskeletal Conference Room (found of the main floor, halfway down the corridor to the left of the cafeteria, marked by an eagle statue). Upcoming meeting dates are as follows:

November 14, 2006	June 12, 2007
January 9, 2007	September 11, 2007
March 13, 2007	November 13, 2007
May 8, 2007	

All members in good standing are welcome to attend these meetings (please notify us by email or phone if you are planning to attend). All meetings start at 7pm and go no later than 10pm.

## **Government News -- fitness tax credit**

Effective January 1st, 2007, a tax credit to promote physical fitness among children will be provided on up to \$500 in fees for programs of physical activity for each eligible child.

## **New camp for physically disabled**

A Calgary based non-profit group wants to build a huge camp in north-east Edmonton where up to 40,000 disabled children a year could stay at a reduced fee.

Our Lady Queen of Peace Ranch would feature three lakes for swimming, fishing and rowing, sports fields, about 60 horses for riding, and teepees and cabins that will eventually sleep 600 to 700 kids, board director Patrick Doherty says.

The project is set to go on a scrubby 80-hectare former gravel operation beside the North Saskatchewan River, a rural area bordered by farms and a golf course.

## **UN delegates finalize new treaty protecting rights of persons with disabilities (27 Aug 2006)**

After five years of negotiations, countries meeting at United Nations Headquarters in New York have agreed on a new treaty to protect the rights of persons with disabilities.

“This is the first convention of this magnitude for this century,” UN General Assembly President Jan Eliasson said after the agreement was reached late Friday. He told the negotiators that they were conveying to the world “the message that we want to have a life with dignity for all and that all human beings are all equal.”

“This marks a great day for the UN and for persons with disabilities,” said New Zealand’s Ambassador Don MacKay, who chaired the talks through its final sessions. “It’s a good convention and it will make a difference for millions of people.”

The successful completion of the treaty, after a day of intense negotiations and compromises that capped years of effort, was met with applause by well over a hundred government delegations and hundreds of representatives of disability organizations who participated in the process of crafting the 40-article pact.

Proponents of the convention maintained that the treaty was necessary because persons with disabilities represented one of the most marginalized groups and that their rights had been routinely ignored or denied throughout much of the world.

While the convention does not create new rights, it specifically prohibits discrimination against persons with disabilities in all areas of life, including civil rights, access to justice and the right to education, health services and access to transportation.

The convention was largely approved by consensus, although there was a vote on a provision concerning “foreign occupation” that was included in the preamble. With five countries voting against, the provision was adopted.

It is estimated that 10 per cent of the world’s population, or about 650 million people, suffer from disabilities

## **PLAN Institute Launches Cross-Canada Tour**

To give families the tools they need to secure the well-being of children with disabilities who outlive their parents, The Plan Institute is launching *The Ties That Bind National Tour* this fall. Each stop includes a public screening of the National Film Board documentary “The Ties That Bind,” about an Ottawa family’s struggle to create a secure future for their son. Families can also attend a workshop to learn practical steps that they can take. For dates and locations, visit [www.planinstitute.ca](http://www.planinstitute.ca).

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## **Scholarship News**

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, excellent and enthusiasm in pursuing a future in the broadcast industry. Deadline to apply: Nov. 1. For info, visit

[www.muchmoremusic.com/scholarship](http://www.muchmoremusic.com/scholarship)

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## **Prescriptions at ACH**

Nurses at Alberta Children’s Hospital are NOT authorized to call in new or repeat prescriptions. When you come to clinic, please advise Stephanie if you require refills of regular or ongoing medications so that she can get you in to see the appropriate physician. You may also want to speak to your regular family physician or pediatrician to see if they are comfortable in providing you with ongoing prescription refills.

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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/Independence Fund**

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 at the subsequent board meeting.

