

# Newsletter

Fall 2005



**Spina Bifida and Hydrocephalus  
Association of Southern Alberta**  
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## Take Action - 2006 SB&H Conference

Mark your calendars! The National Spina Bifida & Hydrocephalus Conference will take place in Edmonton September 15-17, 2006.

SBHASA is proud to be hosting this national conference in partnership with the Spina Bifida and Hydrocephalus Association of Northern Alberta. The conference will include:

- Educational sessions
- Social events, including a youth dance
- Keynote speech by Alvin Law
- Day camp for kids and teens
- Silent auction
- Trade show



The conference is taking place at West Edmonton Mall, with plenty of opportunities for shopping and family entertainment. A special conference rate is being offered to conference attendees and their families at the Fantasyland Hotel. We encourage our participants and families to take advantage of all that Fantasyland Hotel and West Edmonton Mall offers.

SBHASA would like to know how many of our members are interested in attending this conference. Please notify our office by email (sbhasa@telus.net) or phone (263-1109) if you think you may attend.

If it is feasible for the association, we may offer some form of funding assistance to members travelling to Edmonton for the conference. More information on potential funding programs will be available in the spring of 2006.

For more information, visit [www.takeaction2006.ca](http://www.takeaction2006.ca), or email the organizers at [info@takeaction2006.ca](mailto:info@takeaction2006.ca).

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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.

## President's Message

I was lucky enough in 2004 to attend the annual SBAA conference in Washington, DC on behalf of the SBHASA. From the opening moments to the final session, the conference was a celebration of shared experience and learning opportunities.

I wish each and every one of our members was able to have this experience. Unfortunately, travelling to the U.S. for four days is just not feasible every year - it's a large commitment of both time and finances, one most of us are unable to make.

SBHASA has joined with SBHANA (Northern Alberta) to host the 2006 National Spina Bifida and Hydrocephalus Conference in Edmonton.

We'd like to give all of our members the opportunity to come together with others in the SB&H community, to make new friends, to educate themselves about new technology and medical practices, to get involved.



The more involvement and feedback we receive from our members, the better we will be able to adequately meet the needs of individuals with spina bifida and hydrocephalus. Please send us your thoughts and ideas on what the association is doing, and let us know if you would be interested in attending this conference.

### Executive Committee:

Douglas O'Muir  
President

Joe Dzurilla  
1st Vice-President

Anthea Crewe  
2nd Vice-President

Gerda McGregor  
Treasurer

Ian Albert  
Secretary

Eleanor Reimer  
Member at Large

Debbie Richter  
Past President

Then mark your calendars for September 15-17, 2006, 'cause we're going to Edmonton!

Have a safe and happy winter,

Douglas O'Muir

## Thank you fundraisers

Thank you to everyone who volunteered their time to do some fundraising for the association during Spina Bifida and Hydrocephalus Awareness Month in June.

Kathy Hawryluk	Wally Hofer
Whitney Pohl	Annie Martens
Verna Unruh	Elaine Oldford
Cherie Helm	Ian Albert
Nolan Wiebe	Linda Albrecht
Natasha Reule	Teresa Smith

Through daisy sales and placement of collection canisters in local business we were able to raise more than \$800.00 for the association. Good work everyone!

## MedicAlert lets you live life

If you have a medical condition, such as a latex allergy, you may be exposed to undue risk in the event of a medical emergency.

First responders and healthcare professionals look for genuine MedicAlert bracelets or necklets, read the information engraved on the back and begin treating you. Using your member ID and the emergency hotline number, they call MedicAlert to get all of your vital medical information that's stored on the MedicAlert database. This service is available from anywhere in the world.

Your confidential medical record can be accessed by paramedics, firefighters, police, physicians and nurses in less than two minutes.

For more information on how to join, or to download a registration form, visit:

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

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

## Upcoming research project - Economics of disability

The SBHASA will be collaborating with researchers at the University of Laval on an upcoming research project titled *The economic dynamics of families who care for a child with a disability*.

The main purpose of this study is to provide policy makers, policy analysts and other groups with information regarding the economic burden of personally borne costs attributable to caring for a disabled child and the context in which they occur. This research will provide relevant information, and accurate data, to support disability-related social policy development in Canada.

The study will examine the economic burden incurred

by families who care for a child with a disability. Economic costs include both time costs (for example: time providing care to the child) and consumption costs (for example: wheelchairs, clothing, medications, modifications to the home) specific to caring for and providing for the needs of a child with a disability.

The SBHASA will be recruiting participants for the study from our membership. We will be sending more information to you once the study's funding is approved by CIHR (Canadian Institutes for Health Research), and anyone who is interested is encouraged to participate.

## New Research Reveals Possible Gene Location for NTDs

Dozens of investigators studying nearly 300 individuals from 44 families across America have narrowed down the hunt for the genes that may cause spina bifida and anencephaly.

The results of the first full genetic analysis of families having two or more related members with neural tube defects (NTDs) have identified several possible locations for genes causing the disorders, particularly on chromosomes 7 and 10. The findings appear in the April 14, 2005 online edition of the *Journal of Medical Genetics*.

Each individual has 23 pairs of chromosomes, each made up of thousands of genes, which in turn consist of DNA molecules. This genetic material determines individual characteristics.

Marcy Speer, PhD, Duke University

Medical Center, and colleagues from across the U.S. screened the genetic makeup of 44 families having at least two related individuals with NTDs. A total of 292 family members were included in the study. DNA samples taken from whole blood were screened for genetic markers on various chromosomes to identify any regions that might harbour defective genes.

The 89 individuals with an NTD had intervals on chromosomes 7 and 10 with the highest scores. In addition, a review of public databases revealed three biologically plausible candidate genes on chromosome 10 that map closely to the identified region. A single family pedigree contributed significantly to the high score on chromosome 7. Other regions of interest were found on chromosomes 11, 15 and 21. The results of

this screening may help prioritize gene assessment for future studies of NTDs.

Of the 23 pairs of chromosomes in the human genome, chromosome 7 is one of the largest, containing about 5 percent of our DNA. Chromosome 10 represents between 4 and 4.5 percent of total DNA in cells.

"We've narrowed down the genome from something huge to initial regions of interest for the NTD candidate genes," said Dr. Speer. She called the study "a hugely collaborative success" that involved hundreds of patients and family members, as well as a large number of investigators in the NTD Collaborative Group - a research consortium of 13 universities and hospitals.

*excerpted from Insights into Spina Bifida July/August 2005*

## Recreational Opportunities

### Therapeutic Riding

The Humblehorse is a new Therapeutic Riding Centre dedicated to special needs children and adults.

The Humblehorse is currently offering a recreational therapeutic riding program geared to special needs children. The focus of the program is to encourage and stimulate physical movement and activity while riding on a horse. Whether playing games or just riding around obstacles, having fun is always the main theme. Each program consists of 6 one hour sessions spread over 6 weeks.

Located 2km west of Strathmore and 1km north of Highway 1. For more information, visit [www.humblehorse.com](http://www.humblehorse.com), or call 934-3738.

### Wheelchair Curling

Last year over 20 athletes with various physical challenges tried curling and the vast majority became very committed to the sport. Over half our members had never even tried curling before and some have returned to a sport they once loved and thought they would never play again.

Players are able to play in both a completely social atmosphere and, if they desire, they can also aim become a highly competitive curler outside of the league play.

This season, some Calgary teams will play in the Alberta Provincial Wheelchair Curling Championships and hopefully (read very likely) they will represent Alberta at the Canadian Championships to be held in February 2006 in British Columbia.

If you are interested in participating, please contact Ernie Comerford (236-3239 or [enjcomerford@shaw.ca](mailto:enjcomerford@shaw.ca)) for more information.

### Wheelchair Basketball

The new season of wheelchair basketball in the East Court Triple Gym at Mount Royal College will start on September 21st, and runs every Wednesday from 7pm-9pm until December 7, 2005. The junior program will run on Tuesdays from 6pm-7pm, starting September 20th.

Please contact Diane ([dsorensen@forzani.com](mailto:dsorensen@forzani.com)) if you are interested in playing, or drop by to see them in action.

### Sledge Hockey

The new sledge hockey season begins October 1st, 2005 at the Stew Hendry Arena in Calgary. The team practices from 6:15-8:15pm every second Saturday. All ages are welcome, and SBHASA owned sleds are available for use by current members.

For more information, contact Jon Bateman ([jonbateman@shaw.ca](mailto:jonbateman@shaw.ca)).



## The UltiMATE Dog Association

Medical studies prove that pets improve the emotional and physical well being of humans.

The UltiMATE Dog Association supports, through dog sports such as agility and flyball, the emotional well being of people with physical challenges. Their goal is to teach handler and dog to compete as a team in these sports.

Agility - consists of a series of obstacles such as tunnels, jumps, teeter totters and elevated walks that the dogs are required to climb, crawl under or jump over.

Flyball - a canine relay race, where dog teams of four race each other down a course over four hurdles, retrieve a ball and run back.

The association's main office is located in the Calgary Canine Centre, located at Glenmore and Blackfoot Trails. The facility includes a matted training floor, doggie day care, retail space, self-serve pet wash and grooming area.

The teaching methods incorporated in the program are positive and motivational for both the handler and the dog.

Participants with physical challenges will be taught appropriate handling techniques that will accommodate their specific mobility requirements.

[www.ultimatedog.org](http://www.ultimatedog.org)



[www.snomobilewear.com](http://www.snomobilewear.com)

- An elasticized foot pouch that slides easily over your shoes
- Opens fully in the back and sides with Velcro fastenings
- Decorative trim and stitching on front and sleeves
- Sizes fit from toddler to adult
- Generous child sizing allows for wear over multiple winters
- Detachable (velcro off) foot pouch for persons with some independent mobility

The Sno Mobile Suit tucks compactly into the foot pouch and has a built in carry strap which allows it to be easily hung from the back of your wheelchair when not in use.

## Sno Mobile Snow Suits

Warm and lightweight, the Sno Mobile suit is easy to put on without getting out of your wheelchair. Made to withstand cold winter weather, the Sno Mobile Suit features:

- A wind and water resistant Commander Nylon outer shell
- A warm quilted inner lining
- Rib knit collar and cuff

## Adapted Physical Abilities Programs - Talisman Centre

Achieve your goals! A personal trainer will work one-on-one with you to develop a fitness routine that meets your specific needs. You'll learn adapted activities that work for you and get tips, advice and encouragement so that you can be your personal best.

The Talisman Centre's facilities are designed specifically for people with disabilities, including specialized equipment for accessible workouts such as wheelchair treadmills, upper body ergometers, a stretch mat platform, a two sided staircase, parallel bars, a wall pulley, and equalizer equipment. There are grip aids, a pool lift for ease of access to all pools, shower wheelchairs, caregiver change rooms, a ramp and handrails into the 30' teach pool, an elevator in the new Wellness Centre to accommodate multiple wheelchairs, a specialized stairwell entry for disabled into new 50m pool, and a ramp and handrails for ease of access into a new 20 person hot tub and whirlpool that is water wheelchair accessible.

[www.talismancentre.com](http://www.talismancentre.com) or phone 233-8393

## ***AISH Update*** (Excerpted from ACCD Fall 2005)

### ***AISH Increase Does Not Apply to Modified AISH***

As you may know, this spring the AISH review committee submitted a report to the Honourable Yvonne Fritz, Minister of Seniors and Community Supports entitled *Renewing AISH*. The report made 11 recommendations to the minister, including a long-awaited increase to the AISH monthly benefit.

Beginning in April, AISH recipients saw their monthly benefit increase from \$850 to \$950 per month, and next April the rate will increase another \$50 to \$1,000 per month.

However, approximately 5% of AISH recipients are part of modified AISH, and will not receive the benefit increase. Modified AISH is a sub-program of AISH and is received by people with a disability who live in care centres such as hospitals, nursing homes, or other facilities listed in the AISH regulations.

The modified AISH benefit includes room and board, a handicap benefit, and any other approved item of need. The room and board component is paid directly to the care centre, and the AISH recipient receives a \$175 handicap benefit for all other expenses.

For more information, visit: [www.seniors.gov.ab.ca/aish](http://www.seniors.gov.ab.ca/aish)

## **Education for Life Bursary**

Are you or someone you know thinking about going to university or college? It's not too early to apply for one of ACCD's (Alberta Committee of Citizens with Disabilities) Education for Life bursaries for the 2006 school year.

Details and application forms can be found on their website at [www.accd.net](http://www.accd.net).

## **Child Disability Benefit**

The Child Disability Benefit is a tax-free benefit of up to \$166.66 per month (\$2,000.00 per year) for low and modest income families who care for a child under age 18 with a severe and prolonged mental or physical impairment.

Families who are eligible for the Canada Child Tax Benefit (CCTB) for a child will receive the CDB only if the child also qualifies for the disability amount, also known as the Disability Tax Credit.

If you receive the CCTB but you have not filed *Form T2201, Disability Tax Credit Certificate* for a child who may be eligible, you must get this form completed and signed by a qualified person.

Visit [www.cra-arc.gc.ca/benefits/disability-e.html](http://www.cra-arc.gc.ca/benefits/disability-e.html) to download the T2201 form and get more information on this program.

## ***Active Leisure for Citizens with Disabilities***

This 2005 National / International Symposium takes place October 12-15 at the Shaw Conference Centre in Edmonton.

The theme of the 4-day symposium is Healthy Communities: Discovering New Landscapes. At the symposium, delegates will celebrate innovations in the parks and recreation sector that are currently addressing the needs of citizens with disabilities.

They will also share strategies, forge partnerships and create opportunities to enhance a culture of wellness and active living for all citizens.

To find out more about the symposium, visit [www.2005.arpaonline.ca](http://www.2005.arpaonline.ca).

## 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.

