

Newsletter

Winter 2006



Spina Bifida and Hydrocephalus
Association of Southern Alberta
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Volunteers Needed

We are looking for volunteers to work at the Elbow River Casino on April 17 & 18, 2006. If you would like to fulfill your volunteer hours this way, please contact our office by phone or email to let us know which day and at what times you are available.

Remember, everyone is expected complete 5 volunteer hours per year in order to be eligible for the SBHASA funding programs.

Take Action - 2006 SB&H Conference

SBHASA is offering a special one-time funding program for families that wish to attend this year's national spina bifida and hydrocephalus conference in Edmonton.

Current members with spina bifida and/or hydrocephalus may apply to have their conference registration fee (individual or family) and accommodations (1 room) at Fantasyland Hotel in Edmonton covered by SBHASA. You are responsible for all other costs related to attending the conference.

Anyone wishing to take advantage of this offer must contact the SBHASA by phone or email before March 15, 2006 at which time we will forward you an application package.

Take Action, the 25th anniversary national conference on spina bifida and hydrocephalus, takes place September 15-17, 2006 in Edmonton. For more information on the conference, visit www.takeaction2006.ca, or email 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

Happy New Year!

I hope that everyone had a good holiday season and is anticipating a great new year. I am looking forward to some exciting things in the new year.

One new thing I am personally involved in is the organisation of the upcoming national conference on spina bifida and hydrocephalus being held in Edmonton this September. This conference will be a great opportunity for everyone to get together and meet other families that are dealing with many of the same issues.



The conference will also have medical information sessions focusing on issues such as surgical interventions for bowel and bladder, dating and relationships, skin care, home accessibility, and adapted sports to name a few. I think you'll find a little bit of something for everyone, and I encourage you to attend.

Please think about getting involved in the SBHASA in some way in 2006. We are always looking for new ideas: a fresh perspective will help to ensure that our association is meeting the needs of our membership.

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

www.sbhasa.ca

Membership Renewals

It's that time of year again. Please be sure to renew your SBHASA membership for 2006. 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.

Please complete the membership form on the opposite page, and send it to our office along with your membership fee.

Vital Card™ - vital information for critical times

Designed by parents of a child with spina bifida and hydrocephalus, the Vital Card is a handy resource for people of all ages - from children to seniors - with these or other serious conditions.

By compiling medical information, insurance numbers and emergency contacts all in one, the Vital Card aims to eliminate stress and miscommunication during the time of an accident or health emergency.

For more information, check out the website:

www.vitalcard.net

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

Accessibility at the Calgary Public Library

excerpted from DDRC newsletter

The Calgary Public Library has acquired a computer workstation called the ALEX (Accessible Library Experience) that provides several assistive hardware and software programs to aid persons with disabilities in exploring the internet, using e-mail, preparing business presentations or writing papers. This technology allows individuals with disabilities to connect to the community through the use of computers, and helps build an inclusive community for everyone.

There are currently nine libraries which have ALEX workstations: Country Hills, Crowfoot, Fish Creek, Forest Lawn, Nose Hill, Shawnessy, Signal Hill, Village Square, and WR Castell Central.

Here are some of the key features of the ALEX:

CCTV (Camera Connection Television) - a camera sends the image of a piece of paper or book placed on a platform to the monitor. The monitor has several buttons to adjust different magnifications and colours to assist with vision barriers.

Kurzweil 3000 - a text to speech reader which has many more functions. Documents are scanned in and the computer "reads" them. The program has spell-check, a dictionary, thesaurus, word prediction, pronunciation software and many other features.

Dragon Naturally Speaking - a speech to text program. An individual talks into a microphone and the spoken words are typed out in text on the computer.

JAWS (Job Access With Speech) - a screen reader that reads out icons, words, pictures and much more when using the computer, giving individuals with a visual impairment full access to the Internet and every other feature the computer offers.

The ALEX is a truly remarkable tool for people with disabilities as it opens up doors and breaks down barriers in the high-tech world.

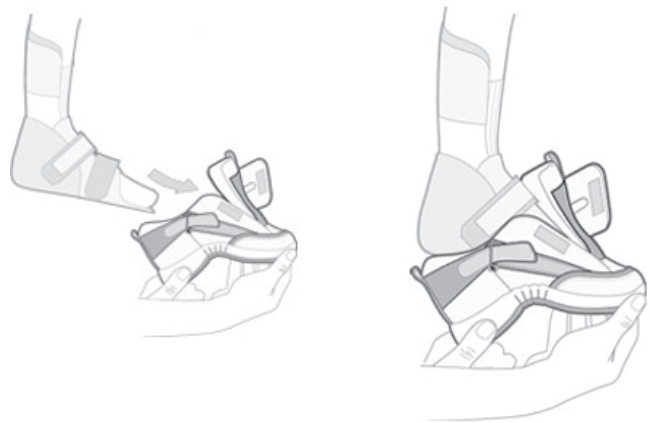
Attention Youth-Artists with Disabilities

If you are interested in mentoring opportunities from other established artists with disabilities, please contact the Canadian Abilities Foundation at <mailto:info@abilities.ca>. Please include your contact information and age in your e-mail. They will send you information pertaining to an up-and-coming project designed to help you in your artistic pursuits!

AFO compatible shoes

Hatchbacks are a line of shoes designed specifically to address the needs of children wearing AFO's, DAFO's, and orthotics.

Designed for ease of entry with the Easy Fit Hinge System, most children will be able to wear their normal shoe size - no more struggling with shoes two sizes too big! The shoe remains firmly closed by a Velcro fastener that is also very easy to use.



The shoes provide extra width around the toe box, extra girth around the ankle, and more room around the heel. Add a lightweight sole, quality materials, extra tough stitching, and great contemporary styling and you have the Hatchback Elite.

www.hatchbacksfootwear.com

Active Living Alliance recruiting youth with disabilities

The Active Living Alliance for Canadians with a Disability (ALA) has applied to be a part of the YMCA Youth Exchanges Canada program. This program will bring together 50 young people from across Canada to Ottawa for the experience of a lifetime. The YMCA Youth Exchanges Canada program is funded by the Department of Canadian Heritage. The event, which is also in partnership with premiere sponsor, Pfizer Canada Inc., the sixth annual ALA Youth Exchange will be held in Ottawa at Carleton University from June 27th to July 3rd, 2006.

Please note: Though ALA anticipates acceptance to the program in March 2006, they are actively searching for potential participants immediately.

The Youth Exchange is a celebration of the diversity of disability and Canadian culture. It exposes participants to a wide variety of active living opportunities, provides a cultural experience through interaction with people from across Canada, and inspires and enhances personal leadership qualities. Participants of the Exchange will have the opportunity to learn about community involvement and the advocacy process.

We encourage SBHASA members between the ages of 14 and 17 as of June 1st, 2006, to sign up before the March 1st, 2006 deadline. Space is limited and preference is given to those who have a disability. You can download the registration forms from their website at www.ala.ca.

Delegates will interact with their peers from coast to coast, learn communication and advocacy skills and participate in events and activities such as rock climbing, table tennis, drumming, yoga and tubing on the Rideau River. The 2005 Exchange was a huge success and garnered rave reviews from participants.

Kristen Barnes, a delegate from the 2004 Exchange writes of the experience "For myself, I have a visual impairment and still do things that I sometimes never expected I'd ever be able to do or accomplish, but seeing the other 49 delegates this week showed me just how much of a future could be out there for anyone with or without a disability."

That confidence is enhanced by educational sessions focusing on communication, goal setting and advocacy. Using a newly developed "Ambassador Advocacy and Speaker's Kit", delegates will learn how to seek opportunities in their home communities and to encourage inclusive, active communities.

The ALACD is a national, non-profit organization formed in 1989. It has 20 national partners and works in every province and territory to promote healthy and active living for Canadians with disabilities.

For more information on the 2006 Youth Exchange contact Nadia Smith at 1-800-771-0663, email at nadia@ala.ca, or log on at www.ala.ca to visit the Active Living Alliance online.

Free online programs for Canadians with disabilities

If you are interested in starting your own business, contact the Canadian Society for Social Development. Programs include: Business Plan Development; Business Management; and Web Design.

One-on-one business coaching and networking are available through instant text messaging, conversation cafés, e-mail and phone.

Visit <http://www.cssd-web.org> for more information.

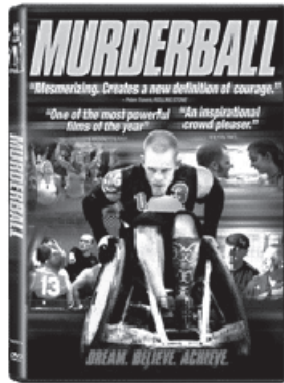
One Smashing Movie

One of the most talked about movies of 2005 is now available on DVD.

Murderball features the human pathos and ego-driven testosterone-fuelled warriors of Hollywood blockbusters like *Gladiator*, but instead of Roman chariots they ride tricked-out, battle-scarred wheelchairs.

Winner of the Audience Award and Best Documentary Feature accolades at the 2005 Sundance Film Festival, *Murderball*, directed by Dana Adam Shapiro and Henry-Alex Rubin, shines a spotlight on quad rugby. It quickly shatters the notion that people who use wheelchairs are weak and passive - these guys are as rude, crude and lewd as any able-bodied professional sports team.

The film is much more than a sports documentary. Three years in the making, it captures intense competition and personal vendettas, but also the drama of relationships, forgiveness and finding meaning after devastating loss.



Much of the action focuses on Mark Zupan, the heavily tattooed, brash and outspoken captain of Team USA, and his rivalry with Joe Soares, a gloryhound and former star player who becomes coach of Team Canada simply to get even. Off the court, Zupan's friendship with the man who accidentally caused his quadriplegia and Soares' clumsy acceptance of his non-athletic teenage son are finely honed subplots.

Rated 14A, *Murderball* is a stunning film with unforgettable personalities that, at 86 minutes, leaves viewers wanting more. DVD special features include "Life According to Zupan," rules of the game, updates on the players and deleted scenes.

www.murderballmovie.com

Health Guide for Adults Living with Spina Bifida

The Spina Bifida Association of America (SBAA) has created a Health Guide for Adults Living with Spina Bifida based on feedback they received from adults across the US.

The workbook addresses the health topics and issues important to adults with spina bifida to help them to manage and maximise their health. You can use this information as a resource to develop your self-care skills and achieve your health goals.

There are 4 sections in the guide:

Feeling Great

- Mental Health
- Learning
- Social Skills
- Sexuality

Looking Good

- Meal Planning and Diet
- Weight Management
- Physical Activity

Living Healthy

- Bladder Care
- Bowel Care
- Head and Spine
- Skin Care
- Latex Allergy
- Sexual Function
- Aging

Managing Your Health

- Being Your Own Advocate
- Preparing for Health Care Visits

You can download the guide from the SBAA website at

www.sbaa.org/site/DocServer/SBAA_Health_GuideCD.pdf

Winter 2006

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

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.

All funding requests for items purchased in 2005 must be submitted by January 31, 2006.

