

Newsletter

Summer 2005



**Spina Bifida and Hydrocephalus
Association of Southern Alberta**
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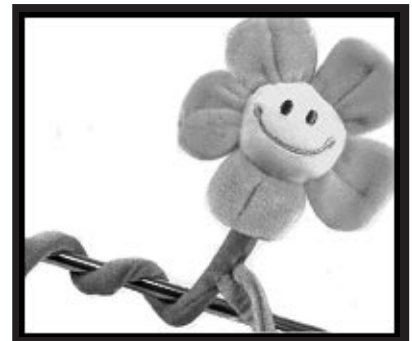
June is Spina Bifida and Hydrocephalus Awareness Month

June is SB&H Awareness month across Canada. Once again, SBHASA member volunteers have placed green fundraising milk cartons around Southern Alberta in an effort to raise money for our general programs (and to complete their volunteer time with the association).

Our information booth will be set up at the Alberta Children's Hospital for 2 weeks in the middle of the month. We are giving out SBH pins and daisy seeds at the booth, as well as distributing information on SBHASA programs and the benefits of folic acid for all women of childbearing age.

Since the daisy is the symbol for spina bifida and hydrocephalus in Canada, we are selling fabric daisies with bendable stems to raise funds and awareness in Southern Alberta. Each \$2 daisy has a card attached explaining the flower's significance to the SBHASA.

Go to our website (www.sbhasa.ca) to get more information and to download an order form to get daisies for all of your friends and family - buy a bunch and save, only \$5 for 3 flowers!



Finally, look for SBHASA awareness posters on Calgary Transit buses and C-trains during the month of June.

Thank you to all of the volunteers who have become involved in these initiatives.

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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

The past year as SBHASA President has been a busy one. The SBHASA Executive Committee has continued to work hard to fulfill our mandate and provide our members with relevant programs.

We carry on towards the goals outlined in our Strategic Plan. This year's budget included funding for the sledge hockey program, purchase of new mobility equipment to share with members, and an increased in dollars allocated for public awareness. We also established a new funding program, the Education Fund, which will help members to reach their educational goals.

We started a new fundraising campaign in 2004. Coin collection canisters were purchased and distributed to members for use during Spina Bifida and Hydrocephalus Awareness Month. This initiative not only increased the amount of non-restricted funds brought in to the association, but gave members another method of fulfilling their volunteer hours. I expect the



program to expand in 2005 as more members become aware of it.

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

At our 2005 AGM held in April, a new Executive Committee was elected. I would like to thank you for giving me the opportunity to serve as President for another year. The SBHASA is a very worthwhile organisation, and being a part of it has been a rewarding experience.

Have a safe and happy summer,

Douglas O'Muir

Membership Renewals

If you haven't already, please renew your SBHASA membership for 2005. 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.

You can download the membership form from our website. Please complete the form, and send it to our office along with your annual fee in order to keep your membership up to date.

Visit the Calgary Zoo this summer

When was the last time you had a chance to visit the Calgary Zoo? Once again this summer, the SBHASA is offering free tickets to get you in the gate!

Each up to date member with spina bifida and / or hydrocephalus can request up to 4 tickets to the Calgary Zoo from the SBHASA. The tickets can be used anytime for general admission to the zoo.

Please contact our office by phone (263-1109) or email (sbhasa@telus.net) if you would like to place an order, and we'll mail you your tickets.

www.sbhasa.ca

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Accessible Summer Fun

After the snow finally melted, Albertans contemplated options available for their summer holidays. Here are some fun family ideas for you to check out:

www.explorealberta.com - an index of over 615 Alberta campgrounds including links to many campground websites. This site allows users to search for specifics such as accessibility, number of sites available, and preferred surroundings.

www.travelalberta.com - a list of resources about vacationing in Alberta.

www.challengerpark.com - Calgary's Rotary Challenger Park has tons of accessible activities, including all day summer camps where children can enjoy a number of different recreation and sport activities.

www.vrri.org - The VRRRI Recreation Centre is a barrier-free facility that provides recreation and leisure opportunities to Calgarians of all ages and abilities. Learn to swim in their specially heated salt water therapeutic pool!

www.betweenfriends.ab.ca - Between Friends Club presents Camp Bonaventure, designed for children and youth, ages 5 to 20 years old, with disabilities. Sign up for a fun, challenge-oriented, summer day camp where you'll make new friends while enjoying unique outdoor experiences.

Edmonton takes the lead in accessible play areas

Hats off to the The City of Edmonton, which has established a *Play Area Accessibility Design Standard*.

This progressive policy will ensure that all new play areas constructed on City parkland will be universally designed and incorporate minimum levels of accessibility. What does this mean? Everyone will be able to participate in both ground and elevated play activities, including children with physical disabilities.

The SBHASA hopes that communities in Southern Alberta will soon follow suit, and set up their own policy for setting up inclusive play areas.

For more information on Edmonton's accessible play areas, visit them on the web at

www.edmonton.ca/playgrounds

If you want to follow Edmonton's lead and get things moving towards inclusion in your community, here are some links to organisations that have grants available to help fund the purchase of new playground equipment:

www.safeway.com/more_info.asp - Safeway Public Affairs Sponsorship Program: The primary focus of this program is community and health issues.

www.rmcc.ca - Ronald McDonald House Charities: RMHC will fund the development of accessible play areas to provide children with physical disabilities the benefit of inclusive play.

www.saturncanada.com - Saturn Community Kidspace: To give back to the communities that support them, Saturn decided to help build a playground or two.

www.childrensabilityfund.ab.ca - Barrier Free Playground Grants: This program offers a grant in the amount of \$4,000 to all groups constructing a new playground that includes a wheelchair accessible component.

Send this information to your local city/town council to find out what their policy on accessibility is and how you can get a new playground for your kids!

Alberta Government Renews Commitment to AISH Program

On April 15, Rob Lougheed, Chair of the AISH Review Committee, submitted the committee's report and recommendations to the Honourable Yvonne Fritz, Minister of Seniors and Community Supports. The report comes after a review process that began in September 2004 and involved over 18,000 Albertans, including 10,000 AISH recipients.

While the recommendations (see below) begin to address AISH recipients' most pressing financial concerns, Albertans with disabilities still face many barriers in areas such as housing, healthcare, employment, and transportation.

excerpted from ACCD Action Notes, May 2005

AISH Review Committee Makes Eleven Recommendations

1. Increase the monthly maximum financial benefit for all clients to \$1,000, then to \$1,025 effective April 2006. Starting in 2007, conduct bi-annual reviews of the benefit rate.

Government Response: Accepted in a modified form: Phase One: \$950 April 2005; Phase Two: \$1,000 April 2006. Will conduct bi-annual reviews starting in 2007

2. Provide supplementary benefits as part of the AISH program, in addition to the base financial benefit, to AISH clients with liquid assets of less than \$3,000 (e.g. medical/surgical supplies, family supplement, and special diet).

Government Response: Accepted as of October 2005

3. Increase employment earnings exemptions as follows: increase by \$200 a month for singles and couples, the amount that is fully exempt; increase from 25% to 50% the exemption rate on income over this amount, to a maximum of \$1,000 for singles and \$2,000 for couples

(income earned above these maximum amounts would not be exempt).

Government Response: Accepted as of October 2005

4. Discontinue the requirement that AISH recipients collect Canada Pension Plan (CPP) benefits at age 60.

Government Response: Accepted as of May 2005

5. Review how income is treated under AISH to clarify rules for what income is fully exempt, partially exempt, and not exempt.

Government Response: Accepted as of October 2005

6. Retain the asset limit at \$100,000. (includes cash, savings, property, trusts, etc. AISH recipient can also own a principal residence, a vehicle adapted to the person's disability, and one other family vehicle. Also, includes a review of how trusts are treated within the asset limit.)

Government Response: Accepted

7. Establish contracts with experts to provide advice to AISH staff regarding complex eligibility decisions and to the Citizens' Appeal Panel as required.

Government Response: Accepted as of July 2005

8. AISH staff meet with their clients periodically to identify supports and services in moving towards greater independence.

Government Response: Accepted as of July 2005

9. Improve client service delivery. Government Response: Ongoing

10. Partner with disability organizations to provide ongoing training for AISH staff.

Government Response: Accepted as of September 2005

11. Work collaboratively with partners to better coordinate government supports and services for persons with disabilities.

Government Response: To be determined

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Barrier free design: Creating a bathroom everyone can use

Quite often, bathrooms are too small for anyone, let alone someone using a wheelchair. Enlarging the space is worth considering to create a much more functional room with a spacious feeling. A careful assessment of adjacent spaces, existing walls, plumbing, heating ducts, and electrical wiring must be made to determine what modifications are possible at a reasonable cost. Accurate drawings are needed to show how the new design works and to get quotes from contractors. Like updating your wardrobe, it is sometimes possible to achieve dramatic improvements with simple, inexpensive alterations.

If it is just not possible to expand the bathroom, you could still consider making alterations within the existing space. This can result in improvements that, although may not be ideal, will allow wheelchair access. So what features should you consider? Some general design considerations are outlined below:

Door - Typical bathroom doors are too narrow to allow a wheelchair to pass through. Plus, they usually swing into the bathroom using needed maneuvering space. They can also pose a potential safety hazard: if someone falls against the closed door, it can be very difficult to rescue them. Widen the door to 36" if possible and consider a pocket door or swing the door out. Install a lever handle for easier turning.

Vanity - A typical countertop vanity has cupboards underneath, which prevents access with a wheelchair. We often recommend a wall-hung vanity, which is a sink in a countertop with clear space underneath. Other features to consider are offsetting the pipes to the back, providing a set of drawers next to the sink for accessible storage, installing a single-lever tap, and installing the counter at a suitable height for the user.

Toilet - If the standard seat height of 14" or 15" is difficult to manage and a higher seat height is required, options include a raised toilet seat, a toiletwater (a 3 1/2" high molded plas-

tic spacer installed under the toilet base), or a higher toilet. Keep in mind that if a commode chair is ever used over the toilet, the higher seat height may not accommodate one.

Bathtub - Equipment such as bath seats, lifts, and grab bars won't be much help if you can't get over the tub rim. Avoid prefabricated tub surrounds as it is difficult to install grab bars into the wall through them. Provide an adjustable hand-held shower head that will suit both seated and standing persons.

Shower - Consider installing a roll-in shower that doesn't have a lip around the edge, ideally 5'X5' to better accommodate a wheeled shower chair. Slope the shower area gently to a centre drain and install waterproof, non-slip flooring throughout the bathroom to prevent water from infiltrating underneath. Avoid shower doors as these can limit maneuvering and transfer space, and can be awkward to manage when using a mobility aid.

Space requirements - the turning cir-

cle required for a wheelchair is usually 5' in diameter. This varies according to the size and type of wheelchair used, as well as a person's ability to maneuver it. The clear space under the vanity and the space in the wheel-in shower will contribute towards the 5' turning circle. Add additional space by moving out a wall, or installing a wide door in the open wall so that the floor space in the adjacent room can also be used.

Grab bars - When renovating your bathroom, reinforce all of the walls with plywood so that grab bars can be installed anywhere they're needed.

These modifications require careful planning and detailing in order to function properly. There are infinite variations in the layout and therefore endless possibilities. Contact the Accessible Housing Society's Residential Assessment and Design Program (www.ahscalgary.ca) to have an expert recommend a design that will best meet your needs.

excerpted from AHS newsletter, V3I3

Support Services for Post-secondary students with disabilities

In most cases, Alberta post-secondary institutions offer a range of support services to assist people with disabilities to successfully complete their studies. Services likely to be offered on today's campuses:

- academic / career counselling
 - needs assessments (cognitive and achievement)
 - information on campus accessibility
 - information about disability related funding programs
 - referrals to relevant programs and funding agencies
 - classroom support (such as note-takers)
 - assistive services (like tutors, learning strategists, exam accommodations)
 - training in and access to assistive technology
 - mediation assistance
 - advocacy and coordination of services
- Prospective students with disabilities are advised to make contact a few months prior to registration to ensure that appropriate supports are in place. The process will include meeting with a counsellor or student advisor, providing medical and other documentation about your disability, and completing a needs assessment.

To receive a full description of the services that your educational facility offers, or to set up an appointment to meet with a counsellor or student advisor, please refer to this list of Alberta post-secondary institutions. If the school you're interested in isn't listed, check out the Alberta Learning website at www.alis.gov.ab.ca/learning/main.asp

University of Alberta

Specialised Support and Disability Services

Tel: (780) 492-3381 www.ualberta.ca/ssds

University of Calgary

The Disability Resource Centre

Tel: (403) 220-8237 www.ucalgary.ca

University of Lethbridge

Support for Students with Disabilities

Tel: (403) 317-2845 www.uleth.ca

Athabasca University

Access to Students with Disabilities

Tel: 800-788-9041 ext 3424 www.athabascau.ca/asd

Grant MacEwan College

Services to Students with Disabilities

Tel: (780) 497-5063 www.macewan.ca

Keyano College

Services to Students with Special Needs

Tel: 800-251-1408 www.keyano.ca

Medicine Hat College

Special Needs / Disability Services

Tel: (403) 529-3819 www.mhc.ab.ca

Mount Royal Community College

Disability Services

Tel: (403) 440-6868 www.mtroyal.ab.ca

Grande Prairie Regional College

Tel: (780) 539-2062 www.gprc.ab.ca/

Red Deer College

Counselling and Learning Support Services

Tel: (403) 343-4064 www.rdc.ab.ca

Northern Alberta Institute of Technology (NAIT)

Services to Students with Disabilities

Tel: (780) 471-8921 www.nait.ca

Southern Alberta Institute of Technology (SAIT)

Counselling Services and Students with Disabilities

Tel: (403) 284-8125 www.sait.ca

For more information, you may also want to visit the Alberta Committee of Citizens with Disabilities (ACCD) website to download their Resource Guide for Post-Secondary Students with Disabilities:

www.accd.net/resource_guide.htm

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.



SBHASA 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 an official receipt. Falsification of any information will result in automatic rejection of the application.

Applicant's Name: _____

Mailing Address: _____

City: _____ Postal Code: _____

Telephone: _____ Email: _____

Child / Adult with Request: _____

Date of Birth: _____

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

I am applying for: Support Recreation Personal Health Education
Maximum: (\$1,200) (\$300) (\$500) (\$700)

Item requested: _____

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