



Spina Bifida and Hydrocephalus Association of Northern Alberta

Box 35025-10818 Jasper Avenue, Edmonton, AB T5J 0B7
Phone: (780) 451-6921 Email: info@sbhana.org Website: www.sbhana.org

ANNUAL GENERAL MEETING October 26, 2011 2010/2011 ANNUAL REPORT

Our Mission Statement: To improve the quality of life for people affected by spina bifida and hydrocephalus through advocacy, research, education, and support.

ADMINISTRATION

Office:

- Alisha Brown continues to work 30 hours/week as our Program Manager. Her position this year was partially funded by the Community Spirit Grant Program
- Darlene Cathcart was hired as an Office Assistant in November, and has worked 10 hours/week.
- Elaine Chan worked 420 hours over the summer as our Fund Development Coordinator through the Canada Summer Jobs Program through the Federal Government

Membership:

- We now have 245 members on our Membership List (up 25 from last year)
- 122 members renewed their membership during the last fiscal year

Strategic Plan:

- The Board continues to follow the Strategic Plan developed January 20, 2007 under the facilitation of Rob Hagg, Alberta Community Development
- The Board will be conducting another strategic planning session following the 2011 Conference in January, 2012

Fund Development:

- Three highly successful fundraisers held this year:
 - Keegan Benner Golf Tournament (\$6,730 Net Proceeds)
 - Hope Classic (\$11,588 Net Proceeds)
 - Conference Silent Auction (\$11,013 Gross Amount Raised)
- We were funded generously by the Gateway Rotary Club for Camp Freedom
- Received funds through the United Way Employee Designation Program
- Received the following Grants:
 - Community Spirit Grant (\$14,590)
 - Community Investment Operating Grant (\$9,546)
 - Muttart Bursary Program (\$370)
 - Canada Summer Jobs Grant (\$4,130)
- Received the following Funding for Conference:
 - Community Initiatives Program (\$10,000)
 - Estate of Thelma Amy Brown (\$10,000)
 - City of Edmonton Civic Sponsorship (\$10,000)
 - SCI Solutions Fund (\$5000)
 - SickKids Foundation (\$5000)
 - Castledowns Lions Club (\$5000)
 - Accommodation Project (\$3274)



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- Received the following Funding for Conference (Continued):
 - VitaPath Small Grants Program (\$2500)
 - Carbon Steel Buildings (\$1000)
 - Hollister (\$750)
 - Congdon's Aids to Daily Living (\$500)
 - Continental Self Storage (\$500)
 - Paralympic Sports Association (\$400)
 - Spedicath Advertisement (\$400)
 - Specialty Designs (\$200)
 - Ibex Payroll (\$200)

ADVOCACY

- SBHANA is represented at meetings held by the following:
 - Office of Disability Issues
 - Interagency Committee on Recreation for Persons with Special Needs
 - Limelight Film Showcase
 - Alberta Disabilities Forum
- Member of the Alberta Disability Forum
- Member of the Edmonton Regional Coalition for Inclusive Education

RESEARCH

- Circulated results of MOMS Fetal Surgery Study
- Informed eligible members of the SBHANA of opportunities to participate in the research studies such as:
 - Glenrose Rehabilitation Hospital "Family to Family Support Program Survey"
 - U of A Faculty of Rehabilitation Medicine "Rating of Perceived Exertion to Prescribed Training in Wheelchair Users"

COMMUNITY CONSULTATIONS

- Neurological Health Charities of Canada – Neurological clinical Guidelines
- Imagine Canada – Health and Vitality of Canadian Charities
- University of Lethbridge – Non-profit and business partnerships
- City of Edmonton Hargreaves & Associates – Satisfaction with City of Edmonton Community Services
- Council of Canadians with Disabilities – implementing the UN Convention on the Rights of People with Disabilities

COMMUNITY BUILDING

- Wrote letter of support for the U of A Health Sciences Council for the Alberta Neurological Strategy
- Wrote letters of support for iDance towards grants that were applied for
- Wrote a letter of support for the Canadian Paraplegic Association (CPA) for the development of an office complex for associations that provided services for persons with disability
- Wrote a letter of support for Anderson Builders regarding an accessible housing project
- Donated \$100 to the City of Edmonton for (IDDP)



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EDUCATION

SB/H Awareness:

- Gateway Rotary Club – Presentation given by Hayden Fairley, Monica Sneath, and Darlene Cathcart on April 20, 2011
- Participated in the Cerebral Palsy Association Fair on May 14, 2011
- June Awareness Month 2011:
 - Bridge banners were placed on three overpasses around the city (Sherwood Park Freeway & 50th Street, Whitemud Drive & 91 Street, and Yellowhead Trail and 170 Street) by Ken Godbeer, Rebecca Moss, and Lise Johnston
 - Tent cards were put up in cafeterias in the following hospitals: U of A, Royal Alex, North East Community Health Centre, Grey Nuns, Glenrose Rehabilitation Hospital, Fort McMurray Northern Lights Regional Health Centre, Leduc Community Hospital, Fort Saskatchewan Health Care Centre, Sturgeon Community Hospital, Westview Health Centre, and Grande Prairie Queen Elizabeth II Hospital
- Completed Quality of Life Video which highlights the wide range of abilities possessed by individuals with spina bifida and hydrocephalus – Debut at the Dream. Live. Inspire. Conference
- University of Alberta – Department of Occupational Therapy: Cindy Smith presented to students on spina bifida and her family's journey in the Fall of 2011

Educational Assistants Conference:

- The SBHANA participated in the 2010 Educational Assistants Conference on February 25th and 26th at Grant MacEwan College again this year, setting up a display and making Education Manuals available; a new set of laminated photos of spina bifida and hydrocephalus were donated by a nursing student

Spina Bifida and Hydrocephalus National Conference – 30th Anniversary

- 271 participants were registered (90 individuals with spina bifida and/or hydrocephalus – 56 adults & 35 kids/teens)
- 57 registered for the Medical Professional Development event
- 80 volunteers
- Overwhelmingly positive feedback from participants and volunteers

MEMBER SUPPORT

Newsletter:

- Winter & Summer editions published this year with many member contributions

Information Updates:

- Regular emails sent out to membership with *Information Updates and Opportunities* and website kept up to date with current information

Social Activities:

- Christmas Party held November 20, 2010 with 120 people in attendance
- Summer BBQ held in conjunction with the Hope Classic on August 20th, 2011 with 120 people in attendance



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Camp Freedom:

- 12th annual camp was held on July 28th – 31st with 25 campers from Western Canada and 12 volunteers

Support Fund:

- Approved 30 different support fund requests with a total value of \$16,931
- Budget remains at \$18,000/year
- One-year pilot project initiated to fund up to \$500 towards medical/wellness expenses on a one-time or trial basis

Member Education Fund:

- Roxanne Ulanicki received funding to attend a Human Rights Conference in Calgary.
- Six individuals received funding to attend the *Dream. Live. Inspire.* Conference (in addition to the subsidy available).

Scholarship:

- Hayden Fairley and Sarah Shinbine are the recipients for the Dr. Peter Bowen Scholarship, with each receiving \$1000 towards post-secondary education

Wheelchair Loaner Program:

- 2 Quickie Kids wheelchairs available for short-term loans

New Parent/ New to the City Gift Bags:

- Assembled by Sharon Veeneman and distributed through the Spina Bifida Clinic at the Glenrose
- All informational resources are now in an electronic format for easy updating

NoLimits Support Evenings

- Delivered the support evenings 6 times between October 2010 and September 2011 with 44 members participating

Information Referrals

- Numerous calls to the SBHANA office for information and support

SBHAC:

- Renewed our membership with the National association
- Raised \$3,000 through Silent Auction towards Bursary Fund for SBHAC (Still to be donated)
- Donated \$2560 from the Hope Classic National Fundraiser
- Todd Benner represented SBHANA on the SBHAC Board