



Spina Bifida and Hydrocephalus Association of Northern Alberta

Box 35025-11229 Jasper Avenue, Edmonton, AB T5K 2R8

Phone: (780) 451-6921 Email: info@sbhana.org Website: www.sbhana.org

ANNUAL GENERAL MEETING

October 24, 2008

2007/2008 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:

- New location: #305, 11010-101 Street (Subletting from the CPA)
- Alisha Brown working 30 hours/week as our Program Manager
- New mailing address: Box 35025 11229 Jasper Ave, Edmonton AB T5K 2R8

Membership:

- Our membership is now 187 (up an additional 16 members this year)
- 98 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

Fund Development:

- Edmonton Gateway Rotary Club – Sponsored \$13,000 towards Camp Freedom again for 2008, as part of a partnership between Edmonton Gateway Rotary and SBHANA
- Benner Wedding Reception Silent Auction – Raised \$1,915
- Keegan Benner Golf Tournament & Silent Auction – Raised \$2,007
- Fun in the Sun Fundraiser – Raised \$135
- Hope Classic – Raised \$11,589
- Received a \$5,000 Rick Hansen Wheels in Motion Grant for a Quality of Life Video



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ADVOCACY

- SBHANA is represented at meetings held by the following:
 - Office of Disability Issues
 - Interagency Committee on Recreation for Persons with Special Needs
 - Picture this Film Festival
 - Alberta Disability Forum
 - Spinal Cord Injury Treatment Centre Society
- Member of the Alberta Disability Forum
- Member of the Edmonton Regional Coalition for Inclusive Education
- Celebrated Grand Opening of Adult Spina Bifida Clinic June 2008

RESEARCH

- Megan Kooistra was selected as the recipient for the \$1000 *U of A Research Scholarship in Memory of Audrey Steinbring* towards her research in the area of neural tube defects
- Informed eligible members of the SBHANA of opportunity to participate in the research study: A comparison of hydrophilic single use and PVC reused catheters in children with spina bifida (Dr. Kiddoo and Dr. Moore)

EDUCATION

SB/H Awareness:

- International Day of Disabled Persons (IDDP) – Roxanne Ulanicki, Nicole Stefaniszyn, and Harmanie Shairp represented the SBHANA, with a display at City Hall on December 3rd, 2007
- Gateway Rotary Club – Presentation given by Darlene Cathcart and Monica Sneath on Camp Freedom
- June Awareness Month:
 - Bridge banners were placed on three overpasses around the city (Sherwood Park Fwy & 50th St, Whitemud Dr & 119/122 St and Whitemud Dr & 159 St) from June 8-22.
 - A display table with information was up at the Glenrose Hospital from June 9-14.
 - Tent cards were put up in cafeterias in the following hospitals: U of A, Royal Alex, Misericordia, North East Community Health Centre, Grey nuns, Edmonton General, Glenrose, Sturgeon County, Westview Health Centre, Fort Saskatchewan, Leduc, Redwater, Devon, Red Deer, Fort McMurray and Grande Prairie.

Educational Assistants Conference:

- The SBHANA participated in the 2008 Educational Assistants Conference at Grant MacEwan College again this year, setting up a display and making Education Manuals available



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Media Coverage

PRINTED MEDIA:

May 24 2008 - Edmonton Journal

"New Glenrose clinic helps adults stricken with spina bifida"

By: Erika Beauchesne

May 28 2008 - Edmonton Journal

"New clinic eagerly awaited"

Article about choice of word "stricken" in previous article about new Adult Clinic

Letter to the Editor from Maureen Letchford

May 31 2008 - Edmonton Journal

"Wheelchair skills camp offers lessons for children and parents"

Article featuring Sara Brunet-Khan at the wheelbasics wheelchair skills camp

By: Sara Ditta

June 10 2008 - Edmonton Journal

"Spina bifida clinic a lifeline for patients"

Article about new adult clinic featuring Harmanie Shairp & Front Page Photo

By: Jamie Hall

June 10 2008 - 24 Hours

"Clinic gives her a spin"

Article about Harmanie and the adult spina bifida clinic & Front page photo

By: Kristy Brownlee

June 10 2008 - Metro

"Dance 'gave me an ability to be free' "

Article about grand opening of spina bifida clinic and Harmanie

By: Eric Bowling

FALL 2008 - Your Health Magazine

"Won't Back Down"

Article about Roxanne Ulanicki & adult spina bifida clinic

By: Malcolm Azania

TELEVISION MEDIA:

June 9 2008 - CTV News

Report on grand opening of Adult Clinic & Harmanie's story

June 9 2008 - Global TV

Report on grand opening of Adult Clinic & Harmanie's story

September 17 2008 – CTV So You Think You Can Dance Canada

Harmanie's dance competition entry for SYTYCD Canada



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MEMBER SUPPORT

Newsletter:

- Spring & Autumn editions published this year with many member contributions

Social Activities:

- Christmas Party held December 8th, 2007 with 160 people in attendance
- Summer BBQ held in conjunction with the Hope Classic on August 16th, 2008 with 170 people in attendance
- Veteran Moms' Reunion Lunch
- Mom's Night Out (kids 0-12)

Camp Freedom:

- 9th annual camp was held on July 10th – 13th with 23 campers and 16 volunteers

Support Fund:

- Approved 20 different support fund requests with a total value of \$13,739
- Budget still \$15,000/year

Scholarship:

- Nicola Twa is the recipient for the Dr. Peter Bowen Scholarship, receiving \$1000 towards her 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

SBHAC:

- Renewed our membership with the National association
- Donated \$1,000 towards Operating Costs for SBHAC
- Jody Sabroe serving in position of Vice-President for the SBHAC
- Needing an Alberta representative to the SBHAC board
- Alisha Brown has been representing the SBHANA on the Federation Framework

COMMUNITY BUILDING

- Donated \$100 in support of the 2008 Wheelbasics Wheelchair Skills Camp at the Glenrose
- Donated \$500 towards the Paralympic Sports Association, supporting participants with SB/H to attend a Sledge Hockey tournament